BIENNIAL REPORT

AND ACTION PLAN FOR SERVICES FY '91-'92

MISSOURI HEAD INJURY ADVISORY COUNCIL

OFFICE OF ADMINISTRATION

Biennial Report

and
Action Plan for Services

FY'91-'92

Missouri Head Injury Advisory Council
Division of General Services
Office of Administration
P.O. Box 809
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Preface

Each year, hospitals report that close to 5,000 Missourians have sustained a traumatic head or brain injury. Half of those injured will be as the result of motor vehicle crashes. The other half will be caused by falls, sports, recreational, industrial incidents, or assaults or weapons. The majority of those injured are male between the ages of 15-24.

Although the injury is not always visible, a brain injury may cause physical, emotional, intellectual, social and vocational changes. The symptoms of head injury may vary greatly, depending on the extent and location of the injury. Persons with a traumatic head or brain injury may have trouble with short-term memory, attention, communication and judgment. Other cognitive impairments may include problems with reading, writing, perception. Fatigue, mood swings, depression, sexual dysfunction, lack of motivation or inability to self-monitor are all symptoms associated with a traumatic brain injury.

Rehabilitation programs, mostly private, for survivors of head injury and their families began emerging in the early 1980's. These were developed to meet the needs of persons who were now surviving head injuries as the result of improved medical technology and who needed rehabilitation beyond acute hospital or medical care. These programs generally focused on post-acute and transitional living rehabilitation, with some specializing in coma care, and were generally dependent upon the person's ability to pay. Health insurance, worker's compensation, and court settlements are financial resources often used to pay for this type of care.

For those who do not have the ability to pay for these or other types of services and for those who need ongoing services following rehabilitation options have been very limited. In general, it has been difficult for persons with head injury to access the various state/federally funded programs due to eligibility criteria. Many of the programs offer services based on financial eligibility and others offer services to special populations which may not include head injury.

In 1984, the Missouri General Assembly passed a Senate Resolution calling for the establishment of a Joint Interim Committee to study the needs of persons with head injury and their families. The Joint Interim Committee not only learned about the number of Missourians with head injury, causes of head injury and the resulting problems, but also how lacking and fragmented state and private services are.

The state of Missouri began addressing these issues with the

creation of the Missouri Head Injury Advisory Council. On March 5, 1985, upon the recommendation of the Joint Interim Committee, the governor signed an Executive Order establishing the 25 member council. Funding was made available for the council in the supplemental appropriation bill in Fiscal Year 1985.

The council was administratively assigned to the Office of Administration providing a forum for the different state agencies along with consumers, parents, legislators and other professionals to coordinate and to plan for state services.

In 1986, legislation was enacted which defined head injury, established a head and spinal cord injury registry and established the Missouri Head Injury Advisory Council statutorily. "Head injury" or "traumatic head injury" is defined as: "a sudden insult or damage to the brain or its coverings, not of a degenerative nature. Such insult or damage may produce an altered state of consciousness and may result in a decrease of one or more of the following: mental, cognitive, behavioral or physical functioning resulting in partial or total disability. Cerebral vascular accidents, aneurisms and congenital deficits are specifically excluded from this definition")Section 192.735 RSMo).

The council is to be advisory and shall:

(1) Promote meetings and programs for the discussion of reducing the debilitating effects of head injuries and disseminate information in cooperation with any other department, agency or entity on the prevention, evaluation, care, treatment and rehabilitation of persons affected by head injuries;

(2) Study and review current prevention, evaluation, care, treatment and rehabilitation technologies and recommend appropriate preparation, training, retraining and distribution of manpower and resources in the provision of services to head injured persons through private and public residential facilities, day programs and other specialized services;

(3) Recommend what specific methods, means and procedures should be adopted to improve and upgrade the state's service delivery system for head injured citizens of this state;

(4) Participate in developing and disseminating criteria and standards which may be required for future funding or licensing of facilities, day programs and other specialized services for head injured persons in this state; and

(5) Report annually to the commissioner of administration, the governor, and the general assembly on its activities, and on the results of its studies and the recommendations of the council.

This report covers council activities conducted during the period of July 1, 199o through June 30, 1992.

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Summary of Activities

The period of this report covers July 1, 1990 through June 30, 1992, during which time a major accomplishment was achieved. After the third year of introduction, legislation passed to create a head injury service division in state government. The legislators, who are also members of the council, were successful in passing the legislation creating the Division of Injury Prevention, Head Injury Rehabilitation and Local Health Services in the Missouri Department of Health. The bill passed during the 1991 session and the new division became a reality August 28, 1991.

The legislation was introduced to provide a "home" in state government for families and survivors to contact for services. It is envisioned that the division is to either coordinate services which may be available from other state and local agencies or provide either directly or through contracts with non-state agencies those services which are needed, but not available through other state agencies or funding sources.

The Missouri Head Injury Advisory Council will continue to advise all state agencies on policies affecting persons with head injury and their families and continue to be housed in the Office of Administration.

Meanwhile, the Missouri Department of Health, Division of Maternal, Child and Family Health was awarded a federal grant from the Centers for Disease Control and Prevention (CDC) to prevent primary and secondary disabilities due to head and spinal cord injuries; developmental disabilities due to fetal alcohol syndrome; and secondary disabilities due to sickle cell anemia. The three year grant was awarded during the fall of 1991. Federal funds were then available to hire a staff person in the head injury division to develop and implement two service coordination pilot projects.

The federal grant also provides funding to the Division of Health Resources, Department of Health, to expand community injury intervention projects and to evaluate the head and spinal cord injury registry.

A Governor's Alliance for Disabilities Prevention has been appointed to advise the Office of Disabilities Prevention established by the grant to carry out activities designed to plan and coordinate policies and activities to prevent primary and secondary disabilities. The director of the Missouri Head Injury Advisory Council represents the council on the Alliance.

During the 1992 legislative session, the Missouri General Assembly appropriated funding to

Service Development and Expansion

Case Management

the new head injury services division for two case managers/service coordinators. Also, the contract money (general revenue) for community services was transferred from the Missouri Office of Administration to the head injury division beginning July 1, 1992. The head injury division is to deliver services through contracts with community agencies and the Missouri Rehabilitation Center, and to coordinate those and other services through case management/services coordination.

Expansion of Developmental Disabilities Definition

After the passage of legislation in 1990 to expand the definition of developmental disabilities, the director of the Missouri Division of Mental Retardation and Developmental Disabilities appointed a committee to determine eligibility for division services. The division director appointed the chairman of the Missouri Head Injury Advisory Council to serve on the task force, which met throughout 1991.

The new definition includes head injury, increases the age of onset from age 18 to 22 and defines the disability as one which results in substantial functional limitations in two or more of six areas of major life activities and reflects the need for a combination and sequence of special, interdisciplinary, or other services which may be of lifelong or extended duration. The six areas of major life activities assessed are: self-care, receptive and expressive language development and use, learning, self-direction, capacity for independent living or economic self-sufficiency, and mobility.

The task force recommended the use of the Missouri Critical Adaptive Behaviors Inventory (MOCABI) to facilitate eligibility screening by evaluating functioning in the six areas of major life activities for persons age eighteen or older. It was modified to more adequately assess the functional abilities of persons with head injuries.

The council staff arranged for in-service training on head injury for two regional centers on developmental disabilities and for the training to be video taped by the Department of Mental Health so that the training can be available to staff from all eleven regional centers.

Special Education

During October 1991, the Missouri Department of Elementary and Secondary Education appointed an advisory committee to develop a definition and a set of eligibility criteria to be used by public school districts throughout the state to identify those children with traumatic brain injury who may be eligible for special education and related services. The Missouri Head Injury Advisory Council and its director participated in that process.

The task force was created in response to Public Law 101-476, the Reauthorization of the Education of the Handicapped Act (referred to as P.L. 94-142) which included traumatic brain injury as a separate

disability. The task force also drafted a manual on head injury for educators.

During the council's seventh annual conference, a day long session, co-sponsored by the Missouri Division of Special Education, was held featuring topics on educational assessment, evaluation, behavior, speech/language and teaching techniques for classroom teachers and special educators.

In 1992, the Missouri Rehabilitation Center, administered by the Missouri Division of Injury Prevention, Head Injury Rehabilitation and Local Health Services, Department of Health, opened an outpatient substance abuse program for persons with head injury.
The program is certified by the Missouri Division of Alcohol and Drug Abuse and funded under the Medicaid program administered by the Missouri Division of Medical Services, Department of Social Services.

The Missouri Rehabilitation Center staff trained three community substance abuse programs, referred to as C-STAR (Comprehensive Substance Treatment and Rehabilitation), on head injury issues in order to provide community follow-up and support once the person is discharged from the Missouri Rehabilitation Center to the community. The Division of Alcohol and Drug Abuse modified its treatment model with assistance from the Missouri Rehabilitation Center staff in order to meet the cognitive and other specialized needs individuals with head injuries may require.

Other activities conducted by the Missouri Head Injury Advisory Council during this two year period include:

Substance Abuse Programs

Professional Development

•Sponsored the statewide workshop, "Developing House Options for Persons with Head Injury", November 2, 1990.

•Co-sponsored with the St. Louis County Productive Living Board for St. Louis County Citizens with Developmental Disabilities an in-service training workshop on head injury for staff from 30 area agencies serving persons with disabilities January 18, 1991.

•Sponsored the Missouri Head Injury Advisory Council Sixth Annual Statewide Conference, "Head Injury: Challenges of the New Decade", May 20-22, 1991.

•Co-sponsored with Missouri Planning Council for Developmental Disabilities and other organizations a teleconference on "Supported Employment and Persons with Traumatic Brain Injury" presented by SET NET, Virginia Commonwealth Universities, Rehabilitation, Research and Training Center. The seminar was held in four locations

Legislation

(Kansas City, Columbia, Springfield and St. Louis) simultaneously September 25, 1991.

•Sponsored Missouri Head Injury Advisory Council Seventh Annual Statewide Conference, "Head Injury: Current Trends & FutureApplications for Education, Rehabilitation and Community Reintegration", May 18-20, 1992.

In addition to the legislation establishing the head injury division, the council supported legislation, which passed, strengthening the DWI (Driving While Intoxicated) law to comply with federal model standards. The council also supported legislation, which failed to pass, requiring the use of seat belts in pick up trucks.

At the federal level the council supported legislation, "The Traumatic Brain Injury Act of 1992", creating funding for state councils, registries, prevention, research, and services. The council also supported legislation which would provide optional coverage under state Medicaid Plans for case management services, provided a state had a state councils and registry.

Public Information and Outreach

The informational handbook, *Missouri Head Injury Guide for Survivors, Families, and Caregivers*, produced by the Missouri Head Injury Association and the Missouri Head Injury Advisory Council was updated, reprinted and distributed (6,000 copies).

The governor signed a proclamation each year proclaiming October as Head Injury Awareness Month. The council updated each year the *Idea Sampler* for head injury awareness month, a joint project with the Missouri Head Injury Association, and distributed it to approximately 40 local organizations and agencies. The sampler contains ideas for promoting head injury awareness.

The council staff continued to publish a newsletter, which is mailed to 5,500 people and continued to provide information and referral materials to families, survivors and professionals.

The council also exhibited information and/ or made presentations on head injury rehabilitation, prevention and available resources at sixteen statewide conferences in addition to the conferences/workshops sponsored or co-sponsored by the council.

The council participated in Day of Concern, an advocacy day sponsored by the Missouri Planning Council on Developmental Disabilities and other advocacy organizations. The event is held at the Missouri State Capitol and provides advocates an opportunity to meet with state legislators and other policy makers.

Service Delivery Model

Description of Service Model and Needs

The Federal Interagency Head Injury Task Force stated in its report that two million Americans sustain a traumatic brain injury each year as the result of motor vehicle crashes, fall, recreational injuries, assaults and violence. Of those who suffer traumatic brain injuries 75,000 to 100,000 die, and 70,000 to 90,000 must live the remainder of their lives with a severe disability.

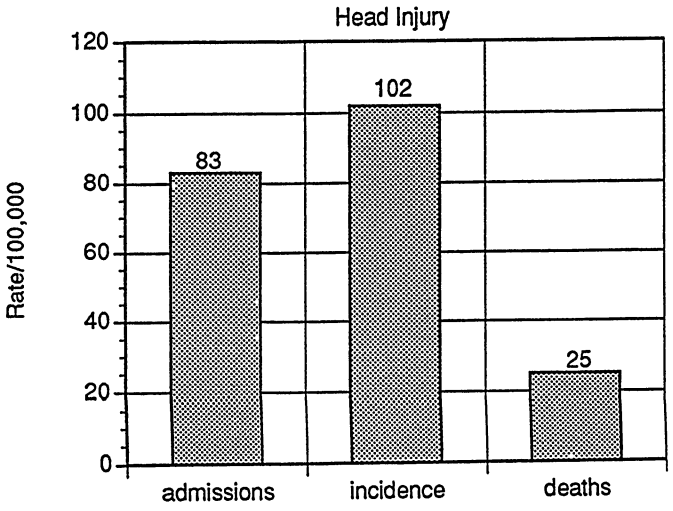
In Missouri, hospitals reported to the Missouri Department of Health, Division of Health Resources that 4,986 persons had received a traumatic head injury during 1992. Of that number 4,086 were hospital admissions and the remaining represent nonhospitalized deaths. A total of 1226 persons died with head injuries, including those who were admitted to a hospital.

The following information regarding the registry is taken from the division's 1992 report. The report, published in 1994, is the first annual report of the Head and Spinal Cord Injury Registry. Though data collection for the registry was begun in July 1987, the data have been too incomplete to develop into a report.

By comparing records to the Hospital Discharge data file, the division believes that the 1992 head and spinal cord injuries were still under-reported by roughly 20-30 percent. To supplement the registry, death certificate (mortality) records that note a head or spinal cord injury are added to the registry, if they are not already represented by the registry records. This adds about 900 records a year to the registry.

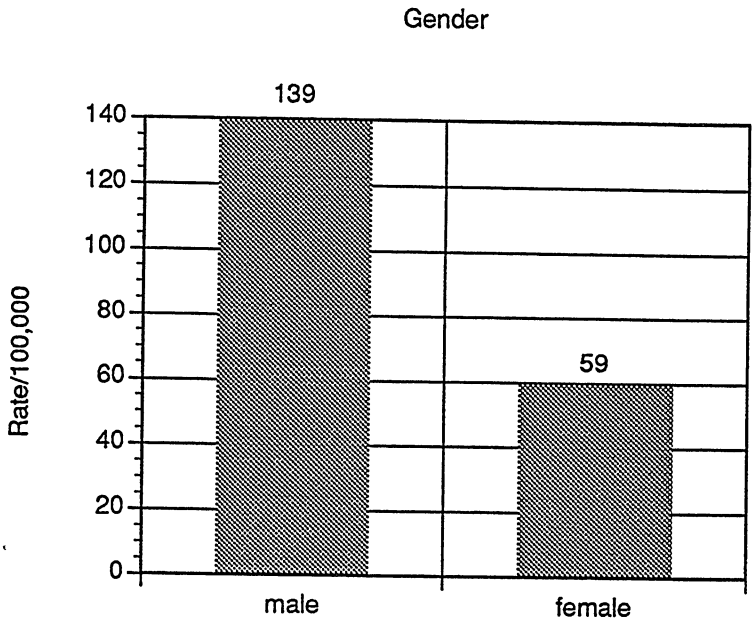
Incidence

From 1991-1992, the incidence rate of head injuries averaged 102/100,000 population. The admission rate was slightly lower at 83, followed by deaths at 25. In comparison, the incidence rate of spinal cord injuries averaged 63/million. The admission rate was 51, and the death rate was 16.

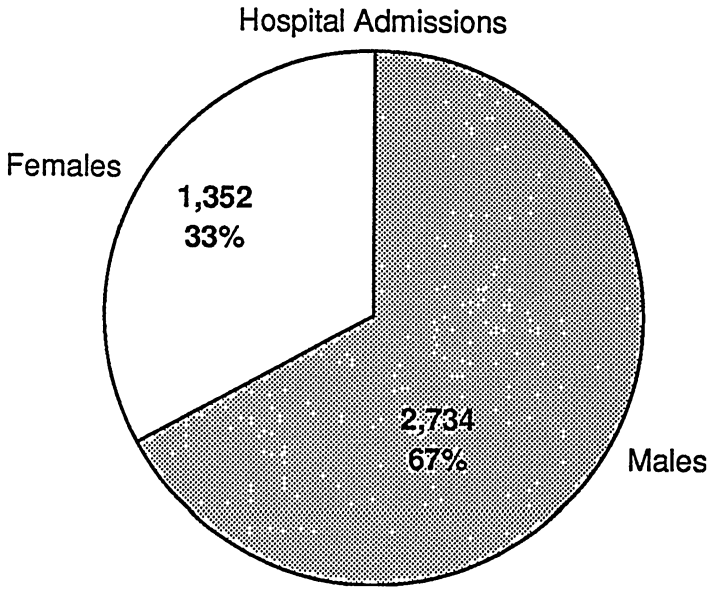


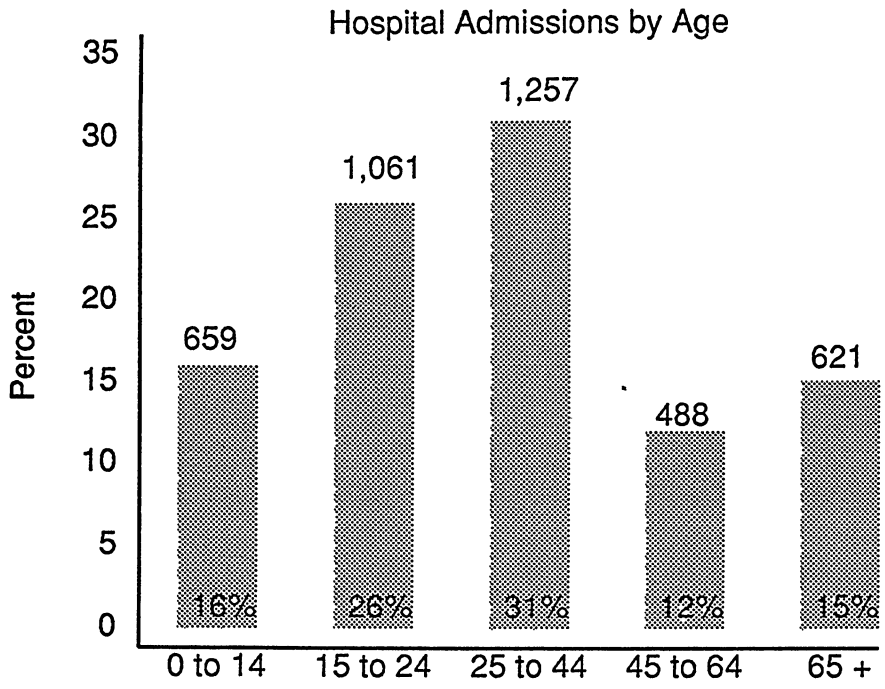
From 1991-192, the incidence rate of head injuries averaged 102/100,000. population.

Profile



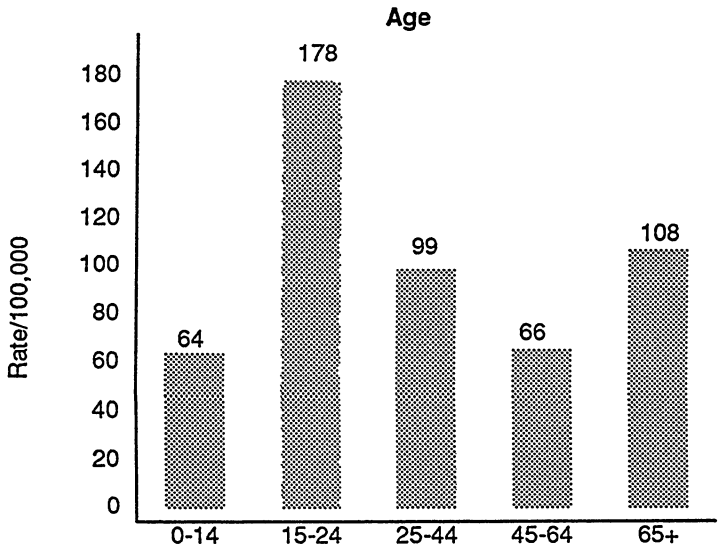
The rate for males was nearly twice that for females; the rate for minorities was 48% higher than that for whites; and the 15-24 age group had the highest head injury rate.

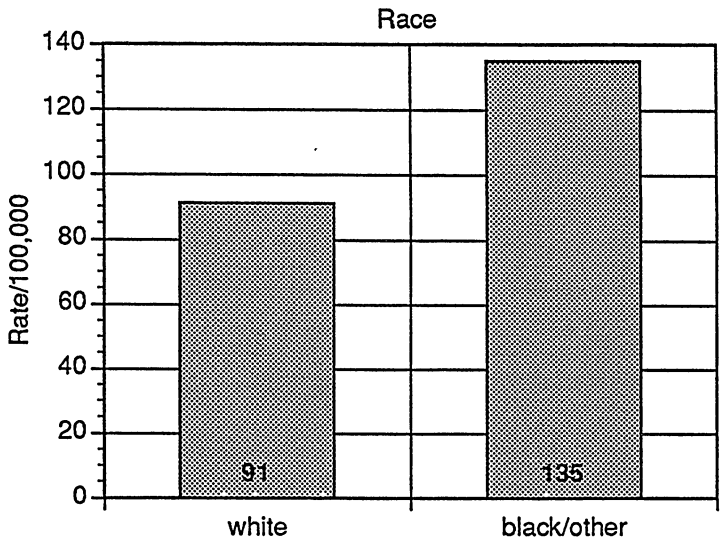




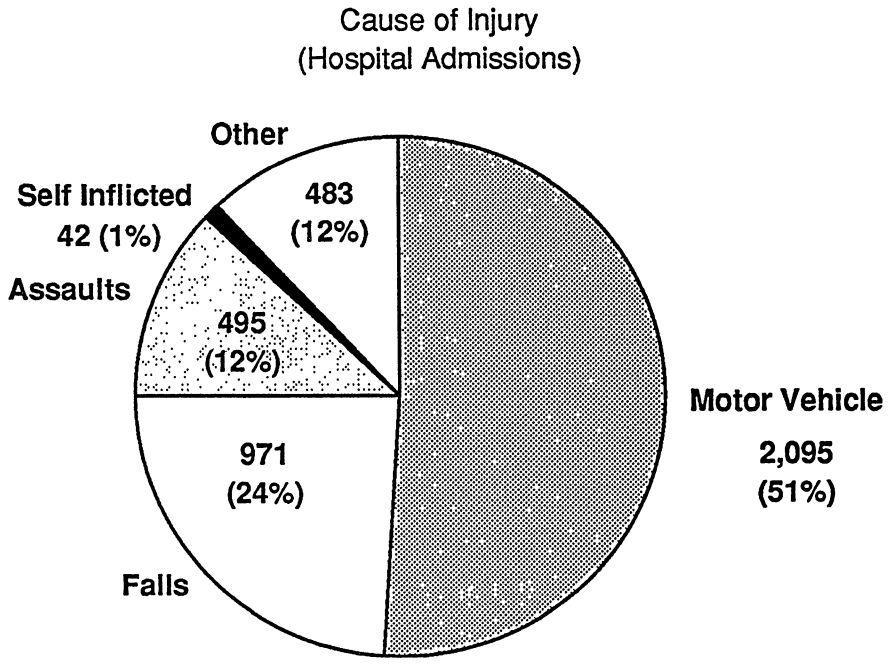
The 1992 registry data shows that head and spinal cord injuries are over-represented primarily among 15-24 year old individuals, and to a lesser extent, young children and older adults. This over-representation is directly related to the causes of the injuries.

Data from the Missouri Head and Spinal Cord Injury reflect other national and state studies / registries in that the 15-25 age group had the highest head injury rate. Data from previous years also show that this is the age group incurring the highest rate of injuries.





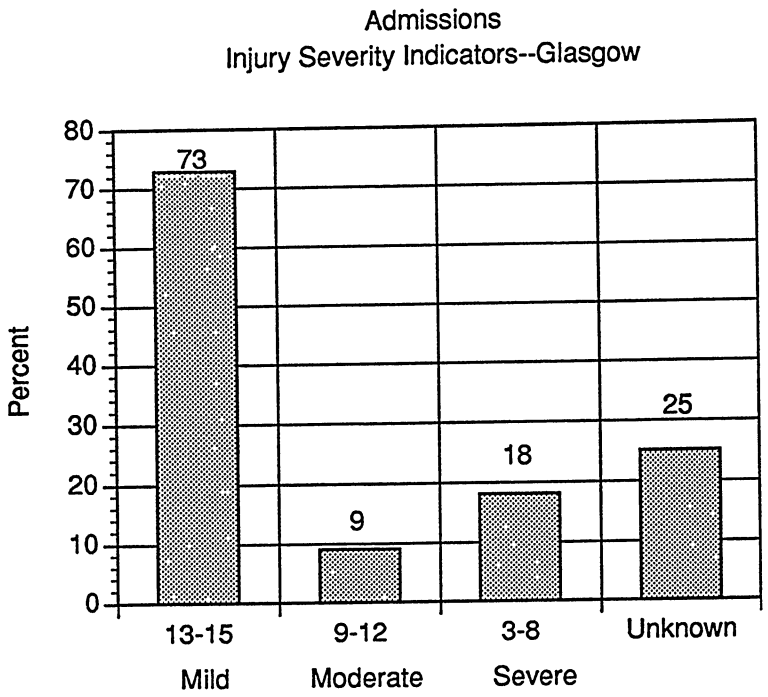
The rate for minorities was 48% higher than for whites. A total of 3,339 persons who are white were admitted to hospitals, while 655 persons who are black were admitted. The rest of the admissions (92) represent persons who are Hispanic, Indian, Asian or were reported as unknown.



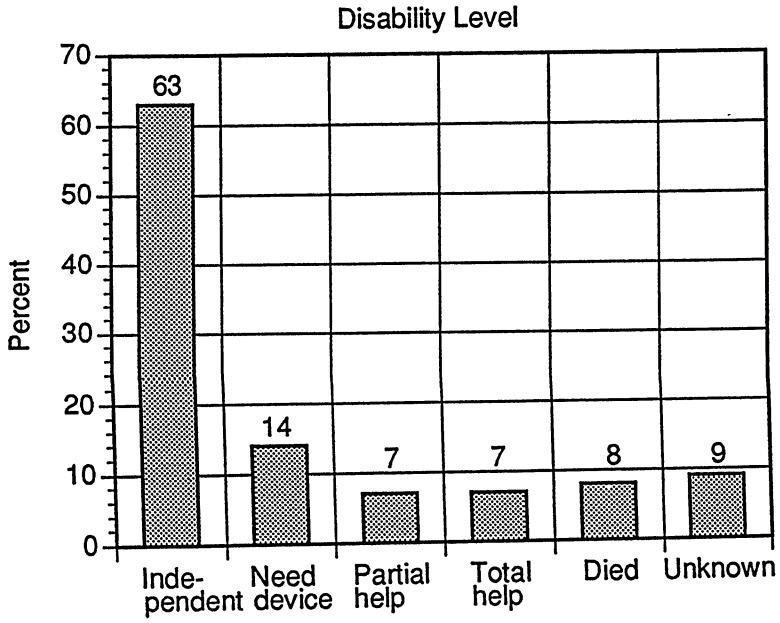
Blood Alcohol Content

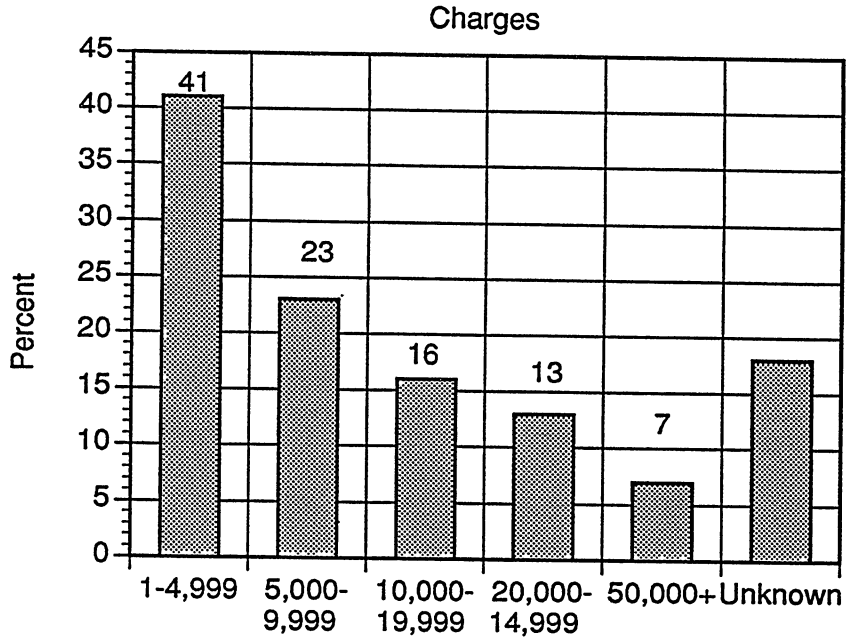
Motor vehicle crashes accounted for half of the injuries, while falls accounted for another 20 percent. Self-inflicted wounds account for 23 percent of head injury deaths, compared to 6 percent of admissions plus non-admitted deaths.

With regard to blood alcohol content assaults have the greatest proportion tested with 58 percent of those tested. Fifty three percent had blood alcohol level of 1% or more (1% is legal definition of driving while intoxicated). As with alcohol, drug testing is greatest among assault cases: 35 % were tested, and of those tested, 46% were positive for drugs.



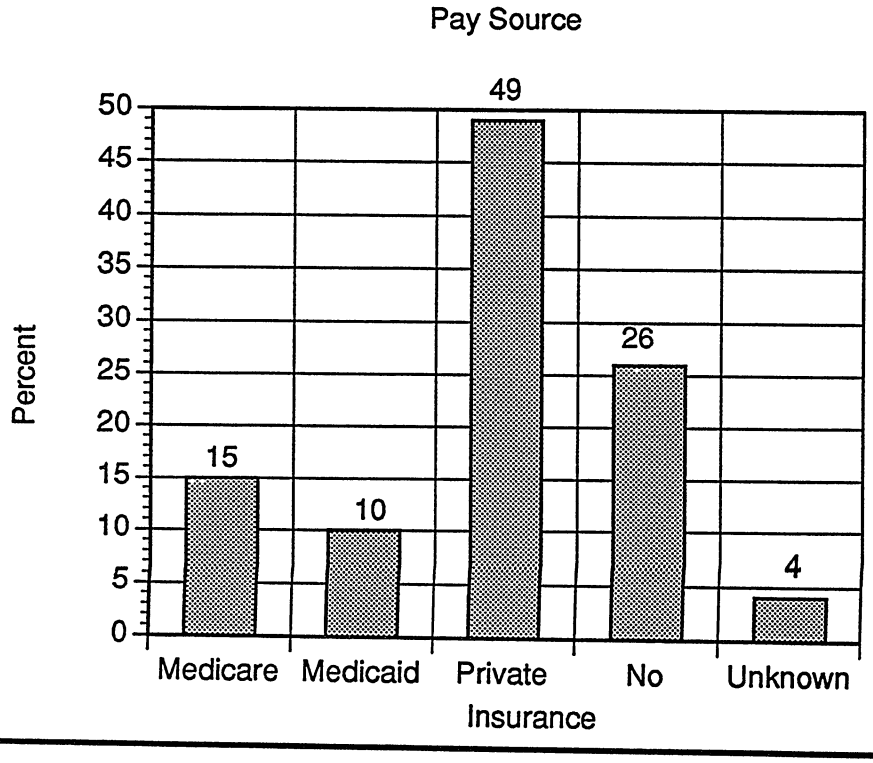
Nearly one in five of the head injuries admissions have a Glasgow score in the severe range. About one in three head injury admissions have an Injury Severity Score (ISS) score in the severe range. Of those persons with head injuries with known outcomes, eight percent died, and seven percent were discharged totally dependent.





Of those with known hospital charges about one in five had charges of at least $20,000. Private pay sources cover only one in two patients with head injuries. One in four have no insurance (self + none), and another one in four report a government pay source.

Eighty-nine percent of patients with a head injury related disability (dependent-total help, dependent-partial help, independent with device) were treated at a trauma center.



Prevalence

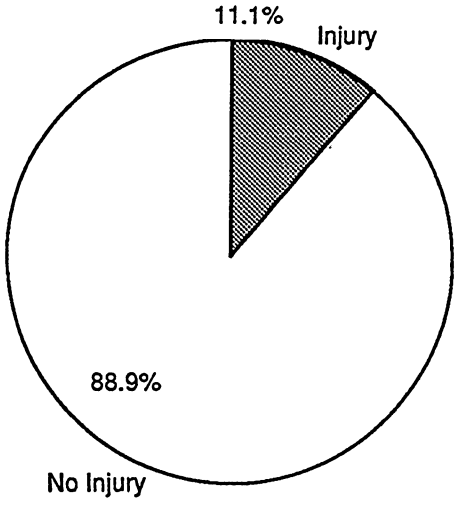
Determining the incidence and prevalence of head injury in Missouri has long been a priority for the Missouri Head Injury Advisory Council. In order to plan for services, the council needs to know not only the type of services, but how many people will need the various programs. From the time the council was created this information has been difficult to determine due in part, to the (1) lack of prevalence studies and (2) omission of head injury in reporting systems.

To address these problems the council initiated two projects: (1) the Missouri Head and Spinal Cord Registry as the result of legislation passed in 1986, and (2) a statewide random telephone poll conducted by the University of Missouri Media Research in 1988.

The purpose of the statewide random telephone poll was to determine: (1) how knowledgeable are Missourians with regard to head injury and (2) how prevalent is head injury in Missouri. A total of 1,123 Missouri residents, 18 years of age or older, were interviewed by telephone between July 11 and August 11, 1988.

The statewide head injury poll asked questions pertaining to three general areas: (1) Generally knowledge about head injury, its causes, and resulting problems; (2) extent of head injury, problems associated with head injury, services received, and services needed, and (3) demographics. With regard to prevalence persons interviewed were asked:

- *Have you personally had a blow to the head which affected your ability to perform routine activities or work?*
- *Has any member of your immediate family had a blow to the head which affected his/her ability to perform routine activities or work?*
- *Do you personally know any Missouri residents who, within the last ten years, has had a blow to the head which affected his or her ability to perform routine activities or work?*



Personally Experienced a Head Injury

Eleven percent of those surveyed (125 persons) said they had personally experienced a head injury. Of these, 62 percent were injured seriously enough to lose consciousness.

Most lost consciousness for only a few minutes, but 17 percent were unconscious for one to three hours, 7 percent were unconscious for four

to 24 hours, while 5 percent were unconscious for an extended period of time.

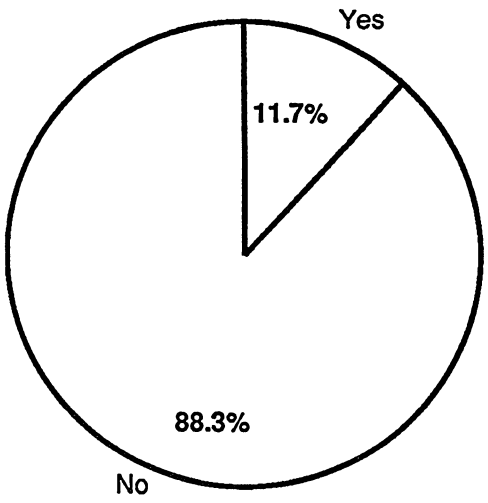
Eighty percent were below the age of 35 when they were injured. In fact, 23 percent were 12 or below and 22 percent were between 13 and 17. Sixteen percent were between 18 and 24, and 19 percent were 25 to 34.

Almost 12 percent of those interviewed said that a member of his immediate family had received a head injury. Of those injured, 75 percent were male household members. Forty-six percent said that his son had been the person injured, while less than 10 percent said his daughter had been injured. Sixty-eight percent said the injured family member had lost consciousness.

Most were unconscious for longer periods of time than those who said they themselves had received a head injury. Almost 26 percent said the family member had not been able to work or go to school continuously for six months since the injury. Fourteen percent were unable to function on their own.

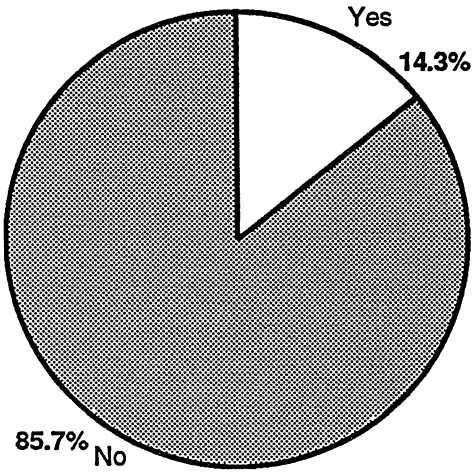
Eighty-eight percent required the care of a physician, and 71 percent required hospitalization. Twenty-seven percent needed rehabilitation, and 15 percent said the family member required psychiatric care or counseling. Seven percent said the family member needed job training, while 8 percent said the family member needed nursing home care.

Immediate Family Member



Nearly 10 percent reported that the family member's medical costs were $50,000 or more.

Knows Someone



Fourteen percent of those surveyed (160 persons) said they knew at least one person who had received a head injury.

Sixty-three percent could recall one victim, while 20 percent could recall two, 9 percent could recall three and 4 percent could recall four.

Four percent knew five or more person. Of those who knew a person with a head injury, 81 percent said the person was a male.

Both the survey and the register indicate that head injuries are a serious public health problem in terms of number of injuries, number of persons with severe disabilities and number of deaths. The fact that they occur primarily among young people makes the problem even more alarming.

Those most at risk for head injuries are children and young adults. Males are more at risk than females. This is most likely the result of life-style among young males. A second group at risk appears to be the elderly, who are more likely to be injured in a fall.

Planning

Since 1985, the Missouri Head Injury Advisory Council has made various recommendations for improving, coordinating and establishing services for individuals with traumatic head injuries and their families. The approach the council has taken to plan for a comprehensive services delivery system is as follows:

- Define/identify individuals with head injury who may need services.
- Define/assess head injury services needed.
- Identify gaps in current state service delivery system.
- Expand and coordinate existing state and private services.
- Develop distinct services not otherwise provided by existing state or private agencies.

The head and spinal cord injury registry allows the state to be in a position to study and address the extent of injury in Missouri and the effectiveness of laws and educational programs directed toward the prevention of injuries. The registry data also provides a mechanism for the state to assess emergency medical services, hospital care and treatment, as well as the extent of injuries and the resulting disabilities.

It is anticipated that through the registry case management/service coordination services may be made available at the time a person is admitted to the hospital.

Data Linkage

Missouri is unique in that the state has five computerized data systems which other states do not have: Missouri Head and Spinal Cord Injury Registry, Statewide Trafficway Accident Reporting System (STARS), Missouri Ambulance Reporting System (MARS), Hospital Admissions System, and the Death Certificates System. Four of these systems are administered by the Department of Health. The fifth system, STARS, is administered by the Missouri State Highway Patrol.

In February 1989, the Missouri Department of Health received

Data Systems

notice of approval of two grants from the National Highway Traffic Safety Administration to link these five data systems for purposes of researching costs of injuries as the result of motor vehicle crashes; contributing factors such as lack of seat belt use and speed; effectiveness of the emergency medical services system; and so forth.

Missouri is one of the first states to receive a contract to link data systems from the scene of the injury to the hospital emergency department. It has also received an additional contract to collect cost data after hospital discharge. The department is conducting the study in cooperation with the Division of Highway Safety, Missouri Highway Patrol Statistical Analysis Center, the Missouri Head Injury Advisory Council and the Missouri Hospital Association.

Data systems which may be useful in planning for the service delivery system include:

Missouri Department of Health

•Missouri Head and Spinal Cord Injury/Trauma Registry (computerized system). All hospitals are mandated to report by state law. The registry requires ICD-9 Codes, E-Code, and Glascow Coma Scale at the time of admittance.

•Death Certificate System (computerized system). The department has added a code to determine if death resulted from a head injury in addition to the E-Code, which was already a requirement.

•Hospital Discharge Data (computerized system). The data set includes ICD-9 Codes. (Approximately 30-40% data also includes E-Code voluntarily.)

•Annual Nursing Home Survey (computerized system). All nursing homes are surveyed annually by way of a questionnaire. The self-questionnaire contains a question with regard to the number of residents with a head injury.

•Special Health Care Needs Program (formerly known as Crippled Children's Services). The reporting system includes ICD-9 codes.

Missouri Department of Labor and Industrial Relations

•Workers' Compensation. Coded if the injury is to the head, however, may be an abrasion as opposed to a brain injury. Also coded if there was a concussion.

Missouri Department of Mental Health

•Division of Mental Retardation and Developmental Disabilities. All clients receive a DSM III-R diagnosis (client intake, computerized system), however, for the most part, mental retardation diagnoses from the DSM III-R are used. The division does not track head injury as a separate category.

•Division of Comprehensive Psychiatric Services. Client intake file for all clients (computerized) and diagnosis is referenced by DSM III-R

code. There is not a specific code for head injury, diagnosis would probably be an Axis 3 (medical) Organic Mental Disorder, which is a broad diagnosis and includes brain injury, tumor, disease, infection. The division would need to look at patient/client record (medical history) to determine head injury.

Missouri Department of Elementary and Secondary Education

•Division of Vocational Rehabilitation. A client intake file (computerized) includes a code for head injury. The disability code is taken from the client's medical reports.

•Division of Special Education. New federal requirements require school districts to report children with head injuries as of Fiscal Year 1993.

Missouri Department of Social Services

Medicaid Claims are computerized and show ICD-9 Codes. (Computerized).

ICD-9=International Classification of Diseases, 9th Revision.

DSM=Diagnostic and Statistical Manual of Mental Disorders, Third Edition Revised.

Array Of Services

The Missouri Head Injury Advisory Council has defined a service delivery system model addressing all of the service components including: **Prevention, emergency medical and medical services, rehabilitation, case management/service coordination, employment, housing, long-term care and community support services.** The council has defined services and organized them into the above categories which are similar to both the medical/health care community and the mental retardation/developmental disabilities service delivery system.

The Missouri Head Injury Advisory Council recognizes that the course of rehabilitation will vary according to the patient's needs and the availability of services. Part of the challenge of providing adequate care for persons who sustain traumatic head injury is the diversity of needs after injury. Post-injury needs can range from full time care to community re-integration.

The order in which services are used can also vary; some people will move from acute medical care into community integration while others may require extended periods of nursing care. Thus, services must be flexible, but also allow for the most frequent progressions.

The service delivery system envisioned by the council is flexible. Rehabilitation of persons who have sustained traumatic head injury is based upon small steps emphasizing increased demands until the person's maximum level of independence is established. While returning to the community living is the ultimate goal, however, it must be recognized that the level of functioning will vary and survivors of head injury may require differing support

services.

Some of these services are in place and are provided by state and private agencies. There are few services and programs following acute, post acute, or functional living rehabilitation for persons who require long-term care or support. Some of the services needed (i.e. housing) are available to other disability groups, but are not available specifically for persons with a head injury.

It has been difficult for persons with head injuries to obtain long-term care and community support services from various state agencies due to eligibility requirements, availability of funding, and availability of service providers experienced in providing services to persons with head injury. Those persons who do have insurance or another third-party payer often find that their third-party coverage does not apply to long-term rehabilitation, long-term care and/or community support services.

Prevention

The National Head Injury Foundation has coined the slogan, "The only cure for head injury is prevention." The incidence and severity of head injury can be reduced through prevention and early intervention activities. Motor vehicle related crashes, bicycles, motorcycles, and off-road vehicles account for over half of all head injuries in Missouri. Falls account for nearly one-fourth of the injuries in 1991-92 and are the second leading cause. Diving injuries, industrial injuries, assaults, weapons and recreational injuries also result in head injuries.

Injury has traditionally been regarded primarily as an unavoidable accident rather than a public health problem. However, injuries can be prevented with a variety of strategies. Three general strategies are available to prevent injuries: (1) *Persuade* persons at risk to alter their behavior, (2) *require* individual behavior change by law or administrative rule and (3) *provide* automatic protection by product and environment design.

In 1983, Congress enacted a law authorizing the secretary of the Department of Transportation to request a study on trauma injury by the National Academy of Sciences. The committee issued the report *Injury in America: A Continuing Health Problem* in 1985. One of the findings of the committee was the lack of the data necessary to allow for the study of the epidemiology of most injuries. The committee believed that systematic data collection is essential for planning and evaluating prevention programs.

In 1988, the U.S. House Committee on Appropriations encouraged the establishment of an Interagency Head Injury Task Force to identify the gaps in research, training and service delivery and recommend

solutions in meeting the needs of persons with a traumatic head injury. The Task Force released its report spring of 1989. In the report the Task Force made five recommendations with regard to primary prevention:

1.) Developing behavioral and environmental interventions aimed at reducing the frequency or severity of traumatic brain injury.

2.) Encouraging the use of both innovative and proven model prevention programs with provisions to evaluate their results.

3.) Encouraging activities that minimize head injury risk in athletics and stimulate the use of helmets (or other protective device) by boxers, bicyclists, motorcyclists, and other high-risk groups.

4.) Evaluating existing societal barriers to the effective implementation of prevention of strategies.

5.) Improving community-level access to existing database systems to assist in designing and developing prevention programs.

The U.S. Department of Health and Human Services in its 1992 report, *Healthy People 2000,* also notes that no single force working alone can accomplish everything needed to reduce injuries and that it requires a combination of efforts including those in the fields of health, education, transportation, law, engineering, architecture and safety sciences. Also, the report notes that alcohol use is intimately associated with the causes and severity of many unintentional injuries.

To address the magnitude of the problem of injuries nationally Congress changed the name of the Centers for Disease Control to Centers for Disease Control and Prevention as part of the Preventive Health Amendments of 1992. The National Center for Injury Prevention and Control was also created. Several grants have been let across the nation to conduct injury research, to establish state injury surveillance systems, and to assist states in developing injury prevention programs.

State Programs

The Missouri Division of Highway Safety was created as the result of the National Highway Safety Act of 1966, and is funded through the Federal Department of Transportation, National Highway Traffic Safety Administration, and the Federal Highway Administration. Its mission is to reduce deaths, injuries and property damage caused by traffic crashes. The division serves as a conduit providing funding and information to law enforcement agencies and community groups throughout the state to achieve its goals.

The division funds several programs aimed at reducing drunk driving, increasing use of child safety seats and seat belts, reducing the amount of speeders, and other

Costs of treatment for selected preventable conditions:

Condition	*Overall magnitude magnitude*	*Avoidable intervention**	*Cost per patient***
Heart disease	7 million with coronary artery disease 500,000 deaths/yr 284,000 bypass procedures/yr	Coronary bypass	$30,000
Cancer	1 million new cases/yr 510,000 deaths/yr	Lung cancer treatment	$29,000
		Cervical cancer treatment	$28,000
Stroke	600,000 strokes/yr 150,000 deaths/yr	Hemiplegia treatment and rehabilitation	$22,000
Injuries	2.3 million hospitalizations/yr 142,500 deaths/yr 177,000 persons with spinal cord injuries in the United States	Quadriplegia treatment and rehabilitation	$570,000 (lifetime)
		Hip fracture treatment	$40,000
		Severe head injury treatment and rehabilitation	$310,000
HIV infection	1-1.5 million infected 118,000 AIDS cases (as of Jan. 1990)	AIDS treatment	$75,000 (lifetime)
Alcoholism	18.5 million abuse alcohol 105,000 alcohol-related deaths/yr	Liver transplant	$250,000
Drug abuse	Regular users: 1-3 million, cocaine 900,000, IV drugs 500,000, heroin Drug-exposed babies: 375,000	Treatment of drug-affected baby	$63,000 (5 years)
Low birth weight baby	260,000 LBWB born/yr 23,000 deaths/yr	Neonatal intensive care for LBWB	$10,000
Inadequate immunization	Lacking basic immunization series: 20-30%, aged 2 and younger 3%, aged 6 and older	Congenital rubella syndrome treatment	$354,000 (lifetime)

*Examples (other interventions may apply).
**Representative first-year costs, except as noted. Not indicated are non-medical costs, such as lost productivity to society.

Source: Data compiled by the U.S. Office of Disease Prevention and Health Promotion and reported in *Healthy People 2000* published by the U.S. Department of Health and Human Services September 1990.

highway safety areas. By educating the public and funding many programs, the division has been able to reduce the fatality rate per 100 million miles traveled from 6.0 in 1968 to 1.9 in 1992.

Through the division's efforts, the state's seat belt usage rate rose to 70 percent in 1992 and Missouri is one of only 14 states to reach this national goal. Nearly 400 organizations across the state received 70 percent seat belt use awards as a part of the national "70% by '92" campaign. As a participating state in the National Operation Buckle Down Program, the division organized 73 law enforcement agencies in their efforts to conduct pre- and post-seat belt use surveys over each holiday period and reported subsequent survey and citation information back to the division.

In February 1992, the division began the "Take a Seat, Please" program in cooperation with the Department of Health, Office of Injury Control and the Missouri State SAFE Kids Coalition. Through this program, individuals who see children not properly restrained write the license plate number of the vehicle being reported on the "Take a Seat, Please" postcard. The postcard is sent in to the state and the Office of Injury Control sends a friendly letter about Missouri's child restraint law. During the first year, 7,000 people were informed of the protection child safety seats provide.

The division funds several programs designed to reduce drinking and driving, including assisting law enforcement with sobriety checkpoints and purchasing some of the equipment needed to conduct the checks. In 1992, the division funded 106 sobriety checkpoints resulting in a total of 4,624 arrests.

The division also produces and distributes many printed materials on a variety of highway safety topics including bicycle safety and pedestrian safety. Types of materials include: fact sheets, posters, brochures, flyers, activity books, coloring books, and lapel pins. Vince and Larry, the nationally known crash dummies, and Buckle Bear costumes are also available for use to community groups through the division. The division also produces and/or distributes radio and TV public service announcements, and press releases to newspapers on all highway safety topics.

The Missouri Department of Health, Division of Health Resources received a capacity development grant September 1989, from Centers for Disease Control and Prevention. The five year grant established a state injury prevention section within the division. The section coordinates prevention programs, evaluates prevention efforts, and coordinates state policy with regard to injury prevention.

An advisory committee was appointed by the director of the

Health Department

State Services for Missourians with Head Injury: A Chronology of Events

1983

- The Missouri Department of Elementary and Secondary Education, Division of Vocational Rehabilitation, assigned a vocational counselor in each district office with the responsibility of working with clients with head injury and began providing in-service training on head injury for DVR counselors.

1984

- The Missouri General Assembly passed Senate Concurrent Resolution 12 creating a Joint Interim Committee on Head Injury during the 1984 legislative session.
- The Joint Interim Committee on Head Injury held statewide hearings with assistance from the Missouri Head Injury Association.

Death Review Teams

Department of Health. Four working committees have developed plans for addressing trafficway injuries, falls and unintentional injuries, intentional injuries, and occupational safety and health. The Missouri Head Injury Advisory Council is represented on this committee.

The Missouri Department of Health, Division of Maternal, Child and Family Health received a federal grant from the Centers for Disease Control and Prevention to establish the Office of Disabilities Prevention during the fall of 1991. The purpose is to coordinate prevention activities for primary and secondary disabilities due to head and spinal cord injuries; developmental disabilities due to fetal alcohol syndrome; and secondary disabilities due to sickle cell anemia.

Activities relating to head injury prevention include the expansion of community intervention projects and the evaluation of the head and spinal cord injury registry. A Governor's Alliance for Disabilities advises the office. The Missouri Head Injury Advisory Council is represented on the Alliance.

During the 1991 legislative session, a bill passed establishing child death review teams in every county to better understand these events and methods for prevention. Missouri became the second state to mandate child death review teams in every county.

The law was in response to the realization that circumstances related to injury deaths to children often remain unreported or inadequately investigates.

All health practitioners, law enforcement officials, social service personnel and any other person with responsibility for the care of children must report any death of a child under the age of 15 to the coroner/ medical examiner.

Because of the multidisciplinary nature of these teams, this is an opportunity for communities to

1985

- The Joint Interim Committee on Head Injury issued the "Report and Recommendations" outlining the extent of and problems associated with head injury, lack of services and recommendations for addressing the problems, including recommendations for prevention strategies.
- The Missouri General Assembly passed the mandatory seat belt law, with a sunset provision, which was signed by the governor March 5, 1985.
- Governor John Ashcroft created the Missouri Head Injury Advisory Council to plan and coordinate services by way of an Executive Order March 5, 1985.
- The Missouri General Assembly appropriated funding (state) in an emergency bill for staff and expenses for the Missouri Head Injury Advisory Council, which was assigned to the Missouri Office of Administration, and funding for Fiscal Year 1986 (beginning July 1, 1985).

develop preventive measures and treatment options for children and families prior to the death of a child.

A State death review team will compile data from these reviews to provide an understanding of the circumstances under which children die from injuries and the degree to which these deaths are preventable.

State Laws

Missouri has several laws designed to reduce fatalities and injuries including: mandatory seat belt law for occupants in the front seat of automobiles, child safety restraints for children under the age of four, motorcycle helmet usage law for all riders and severe penalties for DWI (Drinking While Intoxicated). (The seat belt law does not apply to vehicles licensed as a truck.)

In addition, Missouri has passed legislation requiring all ATV (all terrain vehicle) drivers under the age of 18 to wear a helmet and persons under the age of 16 must be supervised by an adult.

Community Prevention Programs

The Missouri HEADS UP (Missouri Head and Spinal Cord Injury Prevention Project), University of Missouri-Columbia, conducts school assemblies addressing the need for exercising good judgment in order to avoid unnecessary injury. The Project assisted in the making a nationally acclaimed, award winning film called *Harm's Way* featuring young adults from Missouri with head and spinal cord injuries. The University program receives financial assistance from the Missouri Department of Health, Missouri Division of Highway Safety, the Missouri Safety Belt Coalition and other sources.

The prevention program has been modeled in various parts of the state, as well as nationally. The Missouri Head Injury Advisory Council supported expanding the program statewide and has sup-

HEADS UP

- The Missouri General Assembly passed legislation changing the name and mission of the Missouri Chest Hospital, operated by the Missouri Department of Health, to the Missouri Rehabilitation Center (Mt. Vernon). A transitional living unit was created with state funding.
- The Missouri General Assembly appropriated state funding to the Missouri Department of Health for contractual services for persons with head injury for Fiscal Year 1986.
- The Missouri Head Injury Advisory Council held its first meeting September 1985.
- The Missouri Head Injury Advisory Council co-sponsored with the University of Missouri School of Medicine the conference "Head and Spine Injuries and the Epidemic of Trauma in Missouri," October 1985.
- The Missouri Department of Health and the Missouri Office of Administration, Division of Purchasing, issued Request for Proposals for head injury services with assistance from the Missouri Head Injury Advisory Council.

ported the program in its efforts to evaluate the effectiveness of the program. The program has been replicated in Kansas City, St. Louis, Joplin, Springfield and Cape Girardeau and they all cover several counties in Missouri.

SAFE KIDS

The SAFE KIDS program, a national coalition of 65 civic and health organizations was formed to focus on childhood injury. Initiated by Children's Hospital National Medical Center, Washington, D.C., the campaign is supported by Johnson & Johnson and the National Safety Council. In Missouri, there is a statewide coalition and several local SAFE KIDS Campaigns. Cities which have coalitions include Columbia, Kansas City, St. Louis, Jefferson City, Cape Girardeau, Springfield and Moberly (Northeast area).

Head Smart

The National Head Injury Foundation has joined with the American Academy of Pediatrics and the Bicycle Federation of America to launch Head Smart, a national campaign to prevent head injuries through increased use of approved bicycle helmets. Material to promote local awareness is available through the Foundation and the Missouri Head Injury Association.

The Children's Trust Fund, funded through donations, is the principal funder of child abuse prevention programs.

Other educational efforts regarding prevention are conducted statewide and locally by or with support from the Missouri State Highway Patrol, Missouri Safety Council, Missouri Division of Alcohol and Drug Abuse, and the Missouri Division of Highway Safety.

Emergency Medical and Medical Services

The outcome of injury depends not only on its severity, but also on the speed and appropriateness of treatment. Rehabilitation should first begin with the emergency medical

◆The Missouri Department of Elementary and Secondary Education, Division of Special Education, assigned central office staff to work with school districts which have students with head injury.

1986

◆The Missouri Department of Health awarded contracts to seven agencies throughout the state for a variety of head injury services.

◆The Missouri Head Injury Advisory Council defined "head injury" and head injury services and issued the report, Proposed Service Delivery System for Rehabilitation of Missourians with Head Injury: Service and Program Definitions.

◆The Missouri General Assembly passed legislation to establish a head and spinal cord injury registry and to establish the Missouri Head Injury Advisory Council statutorily.

services team at the scene of the injury. Proper attention should be provided in order to prevent further injury. Trained paramedics are able to attend to airways, treat shock, and monitor a patient's condition. They can also notify the receiving hospital regarding the patient's condition and the estimated time of arrival.

The emergency medical services system has improved over the years. Much of the improvements have been attributed to the military which has used triage methods at the scene of the injury and helicopters to transport severely injured patients to receive care in a minimum amount of time during military conflicts. "Communication systems are needed to facilitate decision making, injury management at the site, and the rapid delivery of the patient to a hospital that can provide the needed care," according to the report, *Injury in America: A Continuing Health Problem.*

The Federal Interagency Task Force also recommends: (1) Enhancing the provision of emergency services through training, improved communications and availability of rapid transportation of the injured and (2) ensuring adequate geographical distribution of local acute care trauma facilities.

After the injured is attended to at the site of the injury, he or she is usually, then, transported to the hospital emergency department where the medical team tries to stabilize the patient as well as to diagnose the immediate problems.

For more than a decade the American College of Surgeons has pushed for a regional system of hospital-based trauma centers. A trauma center is a hospital where the medical staff has made a commitment to provide 24-hour "in-house" coverage by surgeons, anethesiologist and supporting staff to care for trauma patients.

Many patients with "minor" head injury may be discharged from the

- The Missouri Head Injury Advisory Council conducted a survey of Missourians with severe head injury served by mental health, home health and nursing home facilities and agencies and issued a report of its findings.
- The Missouri Head Injury Advisory Council published its first newsletter, *Quarterly*.
- The Missouri Head Injury Advisory Council published its first annual report for FY'86.
- The Missouri General Assembly appropriated staff to the Missouri Department of Mental Health, St. Louis State Hospital, for a head injury unit for patients with head injury and aggressive/severe behavior problems for Fiscal Year 1987.
- The Missouri Head Injury Advisory Council held its first annual statewide conference on research, rehabilitation and service needs, "Head Injury: Meeting the Challenges".

emergency department. (Such patients, however, may later experience problems such as headaches, memory disturbances, confusion and disorientation.)

For others who may be more severely injured, surgery may be performed for various reasons. After surgery, the patient may be moved to the intensive care unit for acute care until he or she no longer needs acute monitoring.

If the patient is comatose, he or she may be provided stimulation and physical therapy to prevent deformity or atrophy of the bones and muscles. If the patient appears to be in a persistent vegetative state, or emerging from coma, the hospital may discharge the patient to a nursing facility or to home for the family to provide or arrange for nursing care.

Missouri Trauma Center System

Until legislation passed during the 1987 session, Missouri's trauma center system was voluntary on the part of the hospitals. The Missouri Department of Health developed Trauma Triage Protocol to assist emergency department personnel in the treatment of trauma patients. Like the trauma center program, this protocol was voluntary.

The legislation, which established a trauma center system required the department to develop criteria for a trauma center and to designate trauma centers after an on site review. The legislation also requires licensure of air ambulances and requires all ambulances to transport seriously injured patients to the closest designated trauma center or hospital according to protocol developed by the department.

The legislation established the *State Emergency Medical Services* Council statutorily to assist the department with developing rules and regulations necessary to imple-

1987

- The Missouri General Assembly passed legislation establishing a statewide trauma center system.
- The Missouri Department of Health appointed a committee to develop the form for the head and spinal cord injury registry, trained appropriate hospital staff with regard to the completion of the form, and implemented the registry July 1, 1987.
- The Missouri General Assembly, at the request of the Missouri Department of Health, transferred the appropriation for contractual services to the Missouri Office of Administration, Division of General Services, and contracts were extended by the division.
- The Missouri Department of Elementary and Secondary Education published a manual, *Developing Individual Education Plans for Students Who Have Suffered Traumatic Head Injury: Procedural Guideines*, to assist school districts with students with head injury.

ment the new requirements and to continue to develop recommendations for improving the emergency medical services system. Trauma centers have since been reviewed and designated across the state.

The head and spinal cord injury registry data not only collects data with regard to the number of injuries, but also with regard to method of transportation, length of time in the emergency department, medical treatment provided, disposition of the patient and so forth. Through data collected from the registry, the Department of Health is able to provide hospitals a report listing specific cases identified by audit filters that hospital quality assurance committees may want to review and to take action in order to remediate any potential problem in the emergency and medical care service delivery system.

The Department of Health, Division of Health Resources, through its Bureau of Emergency Medical Services administers the State Ambulance Licensure Law. Its programs includes: (1) Review and approval of curricula at training facilities that offer courses for emergency medical technicians (EMT), mobile emergency medical technicians (MEMT), emergency medical technician paramedics (EMT-P), first responder and corresponding refreshers courses; (2) develop and administer uniform EMT and MEMT certification tests; and (3) develop and coordinate a statewide EMS communications systems.

The statewide emergency medical communications systems includes 141 hospitals with two-way radio capabilities for communicating with ambulances.

This system enables an ambulance attendant to radio a hospital to receive advice from a physician or other emergency department personnel concerning care of an emergency patient that the ambulance transporting.

- The Missouri General Assembly passed legislation allowing sheltered workshops to receive a portion of the state subsidy for employees with disabilities, including persons with head injury, who are unable to work a six hour day.
- The Missouri Attorney General issued an Opinion stating that a person with a head injury would meet the definition of "handicapped" in Section 205.968 RSMo, and, thus, a county mill tax for programs for persons with developmental disabilities or other handicaps could be used to fund programs for persons with head injuries.
- The Missouri Head Injury Advisory Council sponsored its second annual statewide conference, "Head Injury: Focus on the Future".
- The Missouri Head Injury Advisory Council included in its FY'87 Annual Report a state plan for developing a statewide service delivery system for persons with head injury and their families and developed one to five year goals and objectives for the council to undertake in order to obtain a service system.

Rehabilitation

Rehabilitation refers to a comprehensive series of interventions for physical, medical, cognitive, psychological disabilities designed to restore a person to his or her maximum functional potential. This process should begin immediately after the injury as possible. Some general hospitals maintain a rehabilitation unit where physical, speech and occupational therapies are provided. As the patient progresses medically, he may receive such therapies and may be moved to a rehabilitation unit or a separate short-term rehabilitation hospital which, in addition, may also provide cognitive rehabilitation.

The patient may be evaluated by a team of professionals, including a neuropsychologist or psychologist, which, then, develops a rehabilitation program to address the patient's problems. These problems may be related to memory, attention, movement, balance, personality changes, difficulty with complex thinking and with judgment, inappropriate behavior, and difficulty with speech and language. Patients are usually discharged after reaching a plateau of recovery, although many may still require continued rehabilitation beyond the acute stage.

The Federal Interagency Task Force recommendations with regard to rehabilitation are:

1.) Encouraging the continuing review of standards of service for traumatic brain injury clinical care and rehabilitation by appropriate public and private organizations.

2.) Emphasizing outpatient rather than inpatient services for noncritical care and rely on outpatient services at the local level.

3.) Focusing on the ultimate goal of independent function in the community, including training in problem solving and incorporating proven behavior and educational therapies.

4.) Encouraging appropriate

1988

- The Missouri General Assembly passed legislation to expand the state Medicaid program to include comprehensive day services for post trauma patients.
- The Missouri Head Injury Advisory Council recommended and developed a statewide phone survey which was conducted by the University of Missouri-Columbia, School of Journalism, Bureau of Media Research, to determine the awareness and knowledge of the public with regard to head injury and the prevalence of head injury.
- The Missouri Department of Mental Health, Division of Mental Retardation and Developmental Disabilities received approval for a Home and Community Based Medicaid Waiver to allow federal Medicaid reimbursement for certain services for eligible clients to include some of the division clientswith head injury.
- The Missouri General Assembly passed legislation which repealed the sunset provision of the seat belt law.

local and state agencies to mount special efforts to provide counseling for survivors of traumatic brain injury and their families; supportive resources such as day care; traumatic brain injury vocational counseling and training; and specialized treatment in the case of the traumatic brain injured with mental health, alcohol, and substance abuse problems.

5.) Utilizing for traumatic brain injury care appropriate mental health, mental retardation and special education facilities and programs.

6.) Facilitating community reentry by the provision of transitional and supervised residential facilities and programs.

The Missouri Head Injury Advisory Council has defined three types of rehabilitation programs: (1) *Acute Brain Injury Rehabilitation,* (2) *Functional Living Rehabilitation* and (3) *Transitional Living Rehabilitation.*

Most often, after traumatic head injury, the patient goes from acute medical care to *acute rehabilitation* which focuses on physical and gross cognitive deficits. The program is designed to prevent and/or minimize chronic disabilities while restoring the individual to the optimal level of physical, cognitive and behavioral functioning. The rehabilitation program should be carefully coordinated and implemented as soon after onset of injury as is medically feasible.

Acute Rehabilitation

Familes generally need and want information on head injury, expected outcomes, services available and so forth, while their family member is in the hospital. Social workers and discharge planners should assist families in receiving the information and in obtaining the appropriate services following hospital discharge. One of the ongoing discussions of the Missouri Head Injury Advisory Council has been how to link families, who have a member in the hospital, and persons with head

◆The Missouri General Assembly passed legislation requiring persons under 18 to wear a helmet while riding an all-terrain vehicle (ATV); requiring persons under 16 to be supervised by an adult while driving an ATV; prohibiting ATVs on public roads and highways, except under certain conditions; and prohibiting passengers on an ATV.

◆The Missouri Office of Administration, Division of General Services, and the Missouri Head Injury Advisory Council held a public hearing to obtain input for service priorities for head injury contracts.

◆The Missouri Head Injury Advisory Council sponsored its third annual statewide conference, "Head Injury: From Injury to Independence".

◆The Missouri Head Injury Advisory Council chairman established a Task Force on Service Delivery Systems Recommendations to study the need for a division of head injury within state government.

◆The St. Louis State Hospital operated by the Missouri Department of Mental Health, and the Missouri Rehabilitation Center, operated by the Missouri Department of Health, began the process of developing an inter-

injury with services following hospital discharge. Service coordination is viewed as a way to do that.

Post-Acute Rehabilitation

Functional Living Rehabilitation Programs provide intensive rehabilitation with goal directed services to persons who have either completed acute rehabilitation or who have no major acute rehabilitation needs. Emphasis in this program is on functional cognitive, memory, or perceptual deficits, and appropriate interpersonal skills. Services may be delivered on an inpatient (residential) or outpatient (day program) basis.

Transitional Living Rehabilitation

Transitional Living Rehabilitation Programs provide intensive rehabilitation with goal directed services to persons who have sustained traumatic brain injury and who have completed acute and functional living rehabilitation programs or who have no significant need for such services prior to transitional living programs. In these programs, participants would typically move from close observation and supervision to independent living with minimal supervision. Transitional living programs may exist independently or may be part of a larger program. The program should provide safe, accessible housing which allows transition from group living situations to independent living.

The goal of rehabilitation is to enable a survivor of head injury to return to his/her employment/school and to his or her home environment. Many will return to work provided that certain modifications in the work environment take place which will enable the person to return to his or her job. Others will require extensive rehabilitation or programs which specialize in pre-vocational or vocational rehabilitation in order to be able to engage in competitive employment. For those who will not be able to engage in competitive employment without some type of assistance, other alternatives will

agency agreement regarding clients served by each facility, referrals, and coordination of services.

◆The Missouri General Assembly appropriated state funding for the first time to the Missouri Department of Health to expand prevention programs modeled after the Missouri Head and Spinal Cord Injury Prevention Project conducted by the University of Missouri-Columbia.

1989

◆The Missouri Department of Health received two contracts from the National Highway Traffic Safety Administration to link five data files to track patients from the scene of the injury to after hospital discharge and to study costs of injury. The second contract called for researching costs associated with injuries (pre-hospital, hospital, and after discharge).

◆The Missouri Head Injury Advisory Council sponsored its fourth annual conference, "Building Service Delivery Systems for the 90's."

need to be available.

State Programs

Rehabilitation programs for survivors of head injury are relatively new. Most of the programs providing services are private facilities. Several hospitals provide acute rehabilitation and outpatient rehabilitation services such as speech therapy, physical therapy and occupational therapy on a limited basis. A few hospitals and rehabilitation facilities provide functional living rehabilitation services. Most of the programs require the patient or client to have the ability to pay for services or have access to third party pay such as insurance or worker's compensation. For those who do not have the ability to pay the financial resources available or limited.

The Missouri Medicaid program provides very little reimbursement for outpatient therapy services. However, legislation passed during the 1988, session which not only expanded Medicaid eligibility for children, also expanded services to include comprehensive day rehabilitation, defined as post acute (functional living) rehabilitation for trauma patients. Five programs throughout the state have enrolled in the Medicaid program to provide this type of service.

As the result of legislation passed during the 1985 session, the name of the State Chest Hospital was changed to the Missouri Rehabilitation Center. The facility, operated by the Missouri Department of Health, is located in Mt. Vernon. A head injury unit was established January 1986, from a state appropriation designated for that purpose. The Missouri Rehabilitation Center has since expanded its services and provides acute rehabilitation, functional living (residential), transitional rehabilitation, vocational rehabilitation, substance abuse treatment, and a behavior program.

Also during the 1985 session, an

- ◆State legislation was introduced for the first time calling for the establishment of a division of head injury and rehabilitation in the Missouri Department of Health. The bill passed the Senate and fell short by three votes from passing the House of Representatives.
- ◆The Missouri General Assembly appropriated state funding to the Missouri Rehabilitation Center for four beds for persons with head injury with severe behavior problems.
- ◆The Missouri General Assembly appropriated state funding to the Missouri Office of Administration, Division of General Services for long-term support services to enable persons with head injury to participate in the federal supported work program administered by the Missouri Division of Vocational Rehabilitation. Four supported work projects were initially started.
- ◆The Missouri General Assembly passed legislation creating the Missouri Family Trust Fund to allow families and friends of persons with mental or physical disabilities, including head injury, to establish a means for providing for the special needs of persons with disabilities without endangering the persons's eligibility for government assistance.

appropriation ($500,000) was made to the Department of Health for purposes of purchasing services for survivors of head injury during FY'86. For FY'87 the program was reduced to $226,361. The department administered the program for two years, then requested that the appropriation be transferred to the Office of Administration, Division of General Services. The appropriation for contractual services for FY'88 was increased to $314,685 and the same amount was appropriated for FY'89. For FY'90, the Office of Administration, Division of General Services received an additional $207,000 for head injury services with the intention of developing long-term job coaching services for supported employment.

After the program was transferred July 1, 1987, the Office of Administration extended contracts to Rusk Rehabilitation Center, Columbia, and Truman Medical Center-East, Kansas City, for functional rehabilitation services and both programs continue to be under state contract for services. Both programs provide services on an outpatient basis. Both Rusk Rehabilitation Center through its Brain Injury Rehabilitation Program and the Transitional Learning Center, Truman Medical Center-East serve generally eight clients on a daily basis.

There are several private programs providing acute and post-acute rehabilitation (functional rehabilitation) services in hospital settings, a nursing home wing, free standing rehabilitation facilities, and therapies in the home.

Day Programs maintain the intellectual, emotional, social, vocational, and physical capacity of a person who may have received services from an acute rehabilitation, functional living rehabilitation and/or transitional living program, and is unable to maintain a job or participate in a vocational or educational

- The Centers for Disease Control (CDC) approved a four year grant to the Missouri Department of Health for the department to establish a state injury control program.
- The Missouri Head Injury Advisory Council, the Division of Vocational Rehabilitation, and the University of Missouri-Columbia sponsored an in-service training workshop on vocational and supported work issues for community providers.

1990

- The Missouri Office of Administration, Division of Purchasing on behalf of the Division General Services awarded four more state contracts to community agencies for long-term support services for persons with head injury to enable participation in the supported employment program administered by the Missouri Division of Vocational Rehabilitation and to maintain employment following completion of job assessment, job training, and job placement initially funded by the Division of Vocational Rehabilitation.

program.

A day program was established in St. Louis by the Bi-State Chapter of the Missouri Head Injury Association with funding from the head injury state appropriation. The program provides a variety of day program activities to ten persons three days a week.

Pre-vocational/Pre-employment Training readies a person for vocational rehabilitation. The program addresses behavioral and/or cognitive compensation strategies learned through cognitive rehabilitation and/or work adjustment training. This type of program often fills a gap between functional/transitional rehabilitation and vocational rehabilitation services provided by the Missouri Division of Vocational Rehabilitation.

Advent Enterprises, Inc., a not-for-profit corporation in Columbia, provides pre-vocational/employment training and is under contract with the state to provide services to approximately six persons at one given time.

Vocational Rehabilitation readies a person for employment. The federal Rehabilitation Act of 1975, amended in 1992, is administered through the Missouri Department of Elementary and Secondary Education, Division of Vocational Rehabilitation. Vocational rehabilitation is a program designed to help persons with physically or mental disabilities become employable. Many services are provided under the federal program of which some are free and others assessed by the ability to pay.

The 1992 reauthorization Act begins with a presumption of ability, that people can achieve employment regardless of the severity of disability. The process of determining eligibility for rehabilitation services has been streamlined by requiring greater use of existing data available through other agencies, individuals with disabilities and their families.

- The Missouri Head Injury Advisory Council FY'89 Annual Report published in February contained for the first time data from the Missouri Head and Spinal Cord Injury Registry. The data was collected during the 1988 calendar year.
- The Missouri Head Injury Advisory Council directed its Program Planning and Development Committee, Subcommittee on Rehabilitation and Long-Term Care to develop recommendations for expanding in-home care and nursing care to persons with head injury to the Missouri Division of Medical Services.
- The Missouri Head Injury Advisory Council directed its Program Planning and Development Committee, Subcommittee on Community Residential/Employment and Support Services to develop a plan for developing residential services for persons with head injury.
- The Missouri Department of Health appointed a State Injury Control Advisory Committee to work with the State Injury Control Program established by the grant from Centers for Disease Control.

Vocational Rehabilitation

In addition, the revised Act obligates state vocational rehabilitation agencies to (a) complete eligibility determinations within 60 days, except under extenuating circumstances and (b) treat recipients of SSI and/or SSDI benefits as presumptively disabled for purposes of receiving rehabilitation services.

The Division of Vocational Rehabilitation has assigned a vocational rehabilitation counselor in each district office to work with clients with head injury. The division provides on going in-service training regarding head injury to its counselors to assist them in securing appropriate vocational services for survivors of head injury.

The division purchases services from community vendors rather than providing direct services. Several vocational rehabilitation programs serve persons with traumatic head injuries with financial assistance from the division. Services include job training and placement.

Employment

There have been several national studies on the rate of return to work following head injuries and the results have varied. While competitive employment is a goal, often such problems as memory, attention, personality, and interpersonal skills interfere in the achievement of that goal. For others, lack of transportation, housing and other support services may prevent competetive employment. Other alternatives are listed below:

Sheltered Workshop Employment refers to an occupation-oriented facility operated by a not-for-profit corporation, which, except for its staff, employs only persons with a handicap and has a minimum enrollment of at least fifteen employable handicapped persons (Section 178.900 RSMo.). To be eligible persons must be certified by the Division of Vocational Rehabilitation.

Supported Employment refers to

- ◆At the recommendation of the Missouri Head Injury Advisory Council a Request for Proposal was issued by the Missouri Division of Purchasing for purposes of developing an informational handbook for families and survivors of head injury. The handbook (10,000 copies) was produced by the Missouri Head Injury Association with assistance from the council.
- ◆The Missouri General Assembly passed legislation expanding the state definition for developmental disabilities for the Division of Mental Retardation and Developmental Disabilities to include head injury and to change the age of onset from 18 to 22.
- ◆For the second year legislation was introduced in the Missouri General Assembly calling for the establishment of a division of head injury rehabilitation in the Missouri Department of Health. The legislation passed the Missouri Senate, but died on the House calendar.
- ◆The Missouri General Assembly passed legislation establishing a high risk insurance pool for persons who are unable to obtain health insurance because they are considered high risk due to pre-existing conditions.

competitive employment occurring in integrated work settings and being performed by individuals with handicaps for whom either competitive employment has traditionally occurred or competitive employment has been interrupted or become intermittent as the result of a severe disability and which, because of their handicaps, need ongoing job coaching, psycho-social and other support services to perform such work.

State Programs

The Missouri Division of Vocational Rehabilitation receives federal funding for time limited supported work programs. One of the requirements is a demonstration that long term support is available to assist the person in maintaining employment before federal dollars can be used. Supported work programs developed in Missouri for persons with developmental disabilities or mental illness as the Missouri Department of Mental Health and local mill tax boards are able to make some commitment for long term support. However, supported work funding had not been readily available for persons with head injury due to the lack of assurance for long-term support.

During the 1989 legislative session, additional funding was appropriated to the Missouri Office of Administration, Division of General Services for long-term support services to enable persons with head injury to participate in the supported work program funded initially by the Missouri Division of General Services. The Office of Administration, Division of Purchasing awarded eight contracts in 1989, for long-term support programs. With the state commitment for long-term support more persons with head injury is able to participate in the program and will have the necessary support to maintain employment over the long term following completion of supported

Supported Work

- The Missouri Head Injury Advisory Council sponsored its fifth annual statewide conference, "Entering the Decade of the Brain: Head Injury Research, Rehabilitation & Re-entry".
- At the recommendation of the Missouri Head Injury Advisory Council the Missouri Division of Health Resources, as a pilot project, sent an informational letter to persons and families reported by the Missouri Head and Spinal Cord Injury Registry.
- The Missouri Head Injury Advisory Council sponsored a workshop on housing options for survivors of head injury November 1990.
- The Missouri Division of the American Trauma Society sponsored The First Trauma Systems Conference September 1990.
- The Missouri Department of Health, State Injury Control Program sponsored statewide workshops on E-coding (coding for external cause of injury).

work program initially funded by the Division of Vocational Rehabilitation.

Residential Services/ Housing

Ideally, a person suffering from a head injury would return to his/her natural environment following medical and rehabilitation care whether that be to live with a spouse, other family member(s) or independently/ semi-independently. For those who are unable to return to his/her natural environment independently, then some type of housing or support which provides supervision and protection may be needed. Others may require continued rehabilitation, medical, or specialized care provided in a residential setting.

Supported Living

Supported Housing or *Supported Living* is a new, non-traditional approach to housing for adults with disabilities. The concept is founded on several principles, including the principle that people have a right to live in homes of their own with the supports they need. The approach is nonfacility-based and separates the components of housing from support services.

A person with a disability would have a choice as to where to live and support services would be brought to him. The person may lease or rent his house/apartment or own it. Some of the supports which may be needed are defined in this report and include: home health care, personal care, in-home modifications, recreation, transportation, therapeutic and nursing services, crisis intervention, counseling services, dental and medical care, and employment services.

Persons with head injury who may be receiving supported living assistance are generally receiving the service with funding from the Missouri Division of Mental Retardation and Developmental Disabilities and the Division of Comprehensive Psychiatric services. The agencies fund providers to assist the person in

1991

- The Missouri Division of Mental Retardation and Developmental Disabilities Director appointed a committee to determine eligibility in accordance with the new state definition for developmental disabilities for division services and appointed a member of the Missouri Head Injury Advisory Council to the committee.
- The St. Louis Productive Living Board and the Missouri Head Injury Advisory Council sponsored an in-service training workshop on head injury for St. Louis area agencies serving persons with disabilities.
- The Missouri General Assembly passed legislation strengthening the DWI (Driving While Intoxicated) law to comply with federal model standards.
- The Missouri General Assembly passed legislation establishing a Division of Injury Prevention, Head Injury Rehabilitation and Local Health Services in the Department of Health. The Missouri Head Injury Advisory Council will continue to advise all state agencies on policies affecting persons with head injury and their families and continue to be housed in the Office of Administration.

obtaining housing and the supports needed.

Home health care agencies provide three type of services: (1) In-home visits by nurses, which generally are covered by Medicaid or Medicare; (2) homemaker program providing non-medical assistance, such as grocery shopping, to elderly or handicapped persons who would otherwise be in nursing homes, which is a Medicaid service; and (3) private duty (8 hours at a time), which is generally covered by private pay, insurance and sometimes Medicaid.

Personal Care Assistance provides in home assistance which may include help with dressing, bathing, eating or other personal care activities, thus enabling a person to reside in a semi-independent living situation.

State funding is appropriated to the Missouri Division of Vocational Rehabilitation for personal care assistance. The service is provided through the independent living centers.

Respite Care provides temporary relief to the family, thus enabling the family to care for the person in his or her home.

Independent Living Centers may provide counseling and /or supervision on a periodic basis, thus assisting the person with head injury to live semi-independently.

There are five independent living centers throughout the state which provide in varying degrees personal care, in-home care and other independent living services to persons with disabilities. Some of the centers do offer their services to persons with head injury. Services for Independent Living, Columbia, is under contract to provide in-home, counseling and other supervision for those living independently/semi-independently.

Supervised Living Arrangement is a place of residence that substitutes for the individual's own home

Supervised Living

- ◆The Missouri Head Injury Advisory Council sponsored its sixth annual statewide conference, "Head Injury: Challenges of the New Decade."
- ◆The Missouri Planning Council for Developmental Disabilities with assistance from the Missouri Head Injury Advisory Council and other agencies hosted a teleconference in four locations on Supported Employment and Persons with Traumatic Brain Injury presented by SET NET, Virginia Commonwealth Universities—Rehabilitation, Research and Training Center, September 25.
- ◆The Missouri Department of Health received a three year grant from Centers for Disease Control to prevent primary and secondary disabilities. The grant provides funding for a staff person to implement the head injury service coordination system and a component to evaluate the head and spinal cord injury registry.
- ◆ At the recommendation of the Missouri Head Injury Advisory Council the informational handbook, *Missouri Head Injury Guide for Survivors, Families, and Caregivers*, was updated and reprinted (6,000 copies).

or for the home of the individual's family. It should provide environments that are conducive to the development of adaptive behavior, self help and independent living skills. The residence also should facilitate, to the greatest possible extent, continuity with culturally normative living patterns. It should be located within the community and should include both generic and specialized services.

Supervised residential programs (apartment living or group homes) have yet to be developed for survivors of head injury in Missouri. Persons requiring long term care or specialized care have generally sought services from the Missouri Department of Mental Health through its Division of Comprehensive Psychiatric Services and Division of Mental Retardation and Developmental Disabilities and from nursing homes. Some have sought services outside of Missouri. Interest has been expressed in developing supervised living arrangements for persons with head injury.

Structured Residential Placement provides 24-hour care and treatment for those individuals who manifest severe behavior problems. The setting may exist independently or as a part of a larger program.

St. Louis State Hospital, a facility operated by the Missouri Department of Mental Health, has developed a head injury program to serve some head injury patients with aggressive or severe behavior problems. A head injury unit was housed on a ward at the hospital and was originally established to serve the hospital's patients with head injury who had been at the hospital for some time and did not benefit from treatment for mentally ill patients. More recently, the Department of Mental Health has been downsizing its facilities and changing the state hospitals to a psychosocial rehabilitation model. While the state hospital is still recognizing its ser-

- The Missouri Department of Elementary and Secondary Education appointed an advisory committee to develop a definition and a set of eligibility criteria to be used by public school districts to identify those children with traumatic brain injury who may be eligible for special education and related services.

1992

- The Governor appointed the Governor's Alliance for Prevention of Disabilities, which included representation from the Missouri Head Injury Advisory Committee, to advise the Office of Prevention of Disabilities.
- The Missouri Head Injury Advisory Council sponsored its eighth annual conference, "Head Injury: Current Trends & Future Applications for Education, Rehabilitation and Community Reintegration".
- State funding for community head injury services was transferred from the Missouri Office of Administration to the Division of Injury Prevention, Head Injury Rehabilitation and Local Health Services July 1, 1992.
- The Missouri General Assembly appropriated state funding to the Division of Injury Prevention, Head Injury

vices to some persons with traumatic brain injury, the staff is studying how best the program can meet the needs of persons with severe behavior issues.

The state plan for the Division of Psychiatric Services does include goals and objectives with regard to services the division should be providing to persons with traumatic brain injuries. The division recognizes that head injury is a "subpopulation" being served.

During the 1989 legislative session, the Missouri Rehabilitation Center, operated by the Missouri Department of Health, received funding for four beds for persons with head injury with severe behavior problems. The Department of Mental Health and the Department of Health is developing an interagency agreement which will define the level of disability and behavior accepted by the Missouri Rehabilitation Center and the St. Louis State Hospital and how both facilities will coordinate services.

Persons with head injury who also exhibit aggressive and inappropriate behavior find it difficult to locate programs which will accept them due to lack of staff or adequate facility or both. The commitment law which allows the court to commit mentally ill persons who are considered dangerous to self or others does not apply to persons with head injury. Other than St. Louis State Hospital and Missouri Rehabilitation Center, there are no other programs or services in Missouri specializing in severe behavior problems. Persons who require such a program tend to be shifted from facility to facility. Others who are not able to access any program tend to be difficult for the family and the community to manage.

Coma Management/Nursing Programs may accept such individuals once they are medically stable and attempt to achieve improvement by the use of various stimulus

Rehabilitation and Local Health Services for service coordinators/case managers for FY'93.

- The Division of Injury Prevention, Head Injury Rehabilitation and Local Health Services convened a service coordination task force co-chaired by the Missouri Head Injury Advisory Council to make recommendations for a service coordination/case management system.
- The Division of Injury Prevention, Head Injury Rehabilitation and Local Health Services in cooperation with the Missouri Head Injury Advisory Council held public hearings on the proposed service coordination plan.
- Missouri obtained 70% safety belt usage in passenger vehicles.

techniques. Skilled nursing care and physical therapy are important elements of these programs.

Although the Missouri Rehabilitation Center has a few clients who are comatose or in a semi-coma, the facility has not held itself out as having a coma management program. A few nursing homes have accepted patients coming out of coma, but generally the nursing home industry does not believe nursing homes have the staff, in part, due to the costs and reimbursement, to handle this level of care. Some private hospitals and rehabilitation facilities have developed coma management units.

Community Support Services

Community support services provide ongoing or intermittent support to survivors of head injury and their families, thus, enabling them to live in the community on their own or with family or other assistance. These services may exist independently or be part of a larger program. Such services provide ongoing or intermittent support in several areas including recreation, counseling, transportation, therapies, and other support services. Case management/service coordination has been categorized as a support service.

As in other fields, case management/service coordination is viewed by the Missouri Head Injury Advisory Council as playing a major role in the provision of services and should be addressed as a major component of the service delivery system. The legislation establishing the new head injury division in the Missouri Department of Health gives that state agency the responsibility for developing service coordination, as well as other rehabilitation and community support services not provided by other state agencies.

Counseling is an individual or a family intervention to provide psy-

chological support, direction, or change with regard to feelings or thoughts elicited or resulting from brain injury.

Some families and persons with head injury seek counseling services through community mental health centers throughout the state and from private counseling services. The Missouri Head Injury Association through its local chapters offer family support and referral services. The council also provides referral services.

Family Training is a program of training for family members which provides skills to assist the person with a head injury in the family and outside of the home, emphasizing a program of structural activities. In essence, family members are trained to become their own service provider.

Follow-Up provides for the monitoring of clients who have returned to school, home or employment to program. It may be a component of a Functional Living Rehabilitation, Transitional Living or Pre-Vocational Training/Pre-Employment training program.

Transportation refers to the provision of necessary travel accommodations for persons with brain injury to and from places where they are employed or where they receive other services. Transportation may include the provision of driver's education, adaptive automobile devices, and/or training in the use of public transportation systems.

There are a few private rehabilitation programs offering driver's education and evaluation for persons with head injuries.

Recreation/Socialization activities may be provided in specialized programs specifically for persons with head injury or in existing community programs.

The Missouri Head Injury Association sponsors a camp, Wilderness Retreat, during the summer with some assistance from the state. The camp, which consists of two one-week sessions, not only provides socialization and recreation for those have sustained a head injury, but also provides respite for their families and caretakers.

Substance abuse treatment and community support/followup services specifically for persons with head injury are just being developed. Some rehabilitation professionals have noted that traditional substance abuse strategies often do not work with persons with head injury because of cognitive impairments.

In 1992, the Missouri Rehabiitation Center began working with the Missouri Division of Alcohol and Drug Abuse to develop treatment models for persons with head injury. The division modified requirements under C-STAR program (Comprehensive Sustance Treatment and Rehabilitation), which is certified by the division and funded by Medicaid, to accomodate persons with special learning problems.

Substance Abuse Treatment

Case Management

Case management/service coordination is an encompassing process which is the link between the individual, and in many instances the family, and the service delivery system. It is a method that analyzes client and family needs and assesses area resources in order to provide, procure, purchase, and coordinate services for persons with a brain injury. The process must be flexible to allow for the reformulation of service plans relative to changing individual needs.

It allows, and should empower individuals with head injury to remain in their least restrictive environment. Case management/ service coordination generally consists of the following functions: (1) intake; (2) service planning (developing an individualized rehabilitation plan); (3) service coordination; (4) service monitoring/quality assurance; (5) supportive counseling; and, (6) advocacy.

Ideally, service coordinators for persons with head injury would be available throughout the state to assist families and survivors in accessing services and funding necessary for the individual with a head injury to receive rehabilitation and to live in the community. This capability is in the process of being developed by the new head injury division in the Department of Health.

During the 1992 legislative session, funding was appropriated to the Department of Health for two service coordinators for FY'93.

For persons who meet the eligibility criteria for the Department of Mental Health, Division of Mental Retardation and Developmental Disabilities, case management services are provided through the division's eleven regional centers for the developmentally disabled.

Service coordination is also provided by the Department of Health, Bureau of Special Health Care Needs for persons from birth to 21 who qualify medically and financially.

Program Standards

Program Evaluation/Standards/ Certification are the measures against which a program organization or agency is compared to monitor and assess its common practices, quality, and effectiveness in carrying out program and client goals and objectives. The Commission on Accreditation of Rehabilitation Facilities (CARF) has developed national standards for some types of brain injury programs. The standards are voluntary and an agency can apply to CARF for accreditation.

The Missouri Department of Social Services, Division of Aging, licenses nursing homes and the Missouri Department of Health licenses hospitals and rehabilitation hospitals. There are no state standards or licensing requirements for residential programs, day programs

or other specialized services serving clients or patients with head injury.

Pediatrics

Although traumatic head injury is a major cause of disability for children, many professionals interacting with children with head injury are often times unaware of the consequences of head injury. Their needs often go unmet. There needs to be strong coordination and interaction between rehabilitation professionals and the public schools for those children who are school age in order to transition them back to school.

Many times the families need other services which are not traditionally provided in the school setting, such as case management, respite, counseling, and assistance in managing behavior at home. For some, who are seriously injured, families may need medical assistance either in the home setting or in a setting designed to provide a high level of medical care.

Ranken Jordan in St. Louis provides residential care for children with medical needs, including children with head injury. It is the only nursing home for children.

The Medicaid program Health Children and Youth, formerly known as Early and Periodic Screening, Diagnosis and Treatment, provides an array of services for children up to age 21. The Department of Health, Bureau of Special Health Care Needs and the Division of Mental Retardation and Developmental Disabilities offers some services to those children who may be eligible for their services.

Education

The reauthorization of the P.L. 94-142, the Education for All Handicapped Children Act, passed in 1992, requires school districts to report children with traumatic brain injuries. The Missouri Division of Special Education appointed an advisory committee in 1991, to develop a state definition and a set of eligibility criteria for special education services.

Prior to the federal requirement, the division had prepared a manual, *Developing Individual Education Plans for Students Who Have Suffered Traumatic Head Injury,* and assigned staff to assist school districts.

Higher Education/ Adult Education

For Fiscal Year 1992, College for the Living, St. Louis, received a state contract for providing computer skills to persons with head injuries. The computer center offered three semesters of computer education to 30 students. The College is a private, accredited, not-for-profit agency that offers job placement and self-advocacy in addition to the continuing education program.

A transitional program for students with learning disabilities and

students with head injury is offered at Longview Community College, Kansas City. Called Project ABLE, the program offers specialized courses and counseling to teach skills needed to be successful, independent learners. ABLE consists of a structured curriculum including guidance courses to develop social, self-advocacy, and career planning skills; study skills courses, paired with regular college courses; and basic academic skills courses.

The Division of Vocational Rehabilitation provides some financial assistance to persons with disabilities attending college.

Financial Planning

Legislation passed in 1991 establishing the Missouri Family Trust as a way for families to contribute to the care and quality of life for their family members with disabilities without risking the loss of vital government funding, such as Medicaid and Supplemental Security Income (SSI). The Trust accepts contributions from any donor (except the named beneficiary or his/her spouse, which is prohibited by federal law).

The donor names the family member who is disabled and a Co-trustee who works with the Trustees of the Trust to assist the beneficiary. Each year the Trustees, with the consent of the Co-trustees, determine how much income and principal of the Trust shall be used to provide benefits.

In addition to the Family Trust, a Charitable Trust has been established. The Charitable Trust is funded through contributions and is administered by the Family Trust Trustees. It is used to provided benefits to indigent person with disabilities whose families cannot afford to establish an individual trust.

A Board of Trustees oversees the Family Trust and the Charitable Trust and is comprised of nice members appointed by the Governor with the advice and consent of the Senate.

In summary, great gains have been made in the areas of defining services and service needs, developing data capabilities, and prevention efforts. More difficult has been to develop statewide the array of services needed, especially supported housing, community support services and long-term care.

The creation of the new division of head injury in the Department of Health offers the potential of developing those needed services. The new division can begin to develop and purchase those services specific to head injury that are not provided by other state and local agencies.

It will also, through service coordination, assist families in obtaining the array of services needed.

FY'93-95 Goals

Mission Statement

The Missouri Head Injury Advisory Council is appointed by the Governor to promote, study, review and recommend policies to prevent traumatic head injuries and to restore independent and productive lifestyles after traumatic head injury (adopted January 25, 1993).

FY'93-FY'95 Goals

Issue I: Continue Review and Monitor Statewide Service Delivery System

Goal 1: To implement and monitor a case management/service coordination system.

Goal 2: To promote coordination between acute hospitals and acute brain injury rehabilitation programs and between acute brain injury rehabilitation programs, functional living, transitional living programs and community support programs.

Goal 3: To recommend standards for head injury programs receiving state funds.

Issue 2: Prevention

Goal 1: To promote legislation which reduces fatalities and injuries.

Goal 2: To inform the public of the causes and treatment/rehabilitation of head injuries.

Goal 3: To monitor and report incidence and prevalence of head injury.

Goal 4: To study effectiveness of prevention programs.

Issue 3: Early Rehabilitation Care (EMS) and Rehabilitation Services

Goal 1: To monitor emergency medical services and early trauma care in order to reduce secondary injury.

Goal 2: To promote an array of rehabilitation programs accessible statewide.

Goal 3: To study, recommend and promote day activity programs.

Goal 4: To study transportation needs associated with rehabilitation.

Goal 5: To study and recommend appropriate driving education for persons with a head injury.

Issue 4: Education

Goal 1: To study and recommend appropriate educational, including transition services, and other support services for children with head injuries and their families.

Goal 2: To study, recommend and promote programs which offer pre-vocational, vocational and/or vocational rehabilitation services.

Goal 3: To study and recommend program accommodations to assist persons with head injury to participate in higher education.

Goal 4: To promote inservice training for teachers and related school personnel.

Issue 5: Employment

Goal 1: To study, recommend and promote an array of employment opportunities.

Goal 2: To study transportation needs associated with employment.

Issue 6: Residential Services/Supported Housing

Goal 1: To monitor the Department of Mental Health's home and community based Medicaid waiver, which includes housing and community supports.

Goal 2: To study, recommend and promote an array of housing options, including long-term care and residential programs specializing in behavior.

Goal 3: To study transportation needs associated with housing.

Issue 7: Family Support Services

Goal 1: To study, recommend and promote an array of family support services and support services for individuals with traumatic head injury.

Goal 2: To promote usage of home health care and personal care attendant services.

Goal 3: To study, recommend and promote respite care.

Issue 8: Professional Training/Staff Development

Goal 1: To promote opportunities for professionals to expand knowledge on head injury rehabilitation.

Goal 2: To study, recommend and promote assessment teams to use functional evaluation tools with neuropsychological and medical assessment.

Goal 3: To promote staff training on how to manage behavior problems.

Goal 4: To recommend "traumatic brain injury" or "traumatic head injury" as a teacher competency requirement.

Goal 5: To study, recommend and promote the availability of professionals needed for head injury rehabilitation programs (i.e. physical therapists, occupational therapists).

Goal 6: To promote continuing educational programs on head injuries for attorneys and judges.

Issue 9: Legal Issues

Goal 1: To study and recommend appropriate programs for those persons suffering from a head injury considered dangerous to self or others.

Goal 2: To study adequacy of the Guardianship Code in meeting research, treatment and rehabilitation needs.

Issue 10: Health Coverage

Goal 1: To promote health care coverage for survivors of head injury.

Goal 2: To promote Medicaid coverage for rehabilitation and community based services.

Adopted 5/24/93.

About the Council

The Missouri Head Injury Advisory Council is to be comprised of twenty-five members of which twenty-one are appointed by the Governor with advice and consent of the Missouri Senate. The twenty-one members are to represent consumers, families with a member with a head injury, professionals, proprietary schools, private industry, health industry and state agencies which administer programs regarding education, mental health, health, Medicaid, insurance, and public safety. Four members represent the Missouri General Assembly of which two members are state representatives and are appointed by the Speaker of the House of Representatives and two members are state senators appointed by the Senate President Pro-Tempore. The council members elect a chairman and vice chairman for a term of one year in accordance with the bylaws.

Persons who served on the council during Fiscal Years 91 and 92 are as follows:

John F. Allan, Ed.D., Jefferson City, is the Assistant Commissioner (head) of the Division of Special Education, Department of Elementary and Secondary Education. In addition to assisting local school districts with the provision of services to handicapped children, the division is responsible for the state schools for the severely handicapped, state school for the blind, state school for the deaf, and administering the sheltered workshop subsidy. Dr. Allan has been a member since the council was created in 1985.

John Bagby, Ph.D., Jefferson City served as the director of the Department of Health from May 1989 to March 1993. He resigned from the council at the same time he resigned as director.

Perry D. Beason, Ballwin, is employed by the Defense Mapping Agency, St. Louis. He is a survivor of a traumatic brain injury. He was appointed to the council March 1992.

Susan P. Bliss, Columbia, has served on the board of the Missouri Head Injury Association, as Mid-Missouri Chapter president and on numerous Association committees. Other professional memberships include Missouri Association for Children with Learning Disabilities, Council for Exceptional Children and American Society of Training and Development and the Missouri Chapter. She is the parent of a daughter who suffered a head injury in 1975. She was appointed April 1989.

Caroline A. Castillo, Kansas City, received a Bachelor of Arts in Education in psychology in 1985 and a Master of Arts in counseling in 1989. She received a closed head injury in 1980. She resigned from the council in 1991.

Donald M. Claycomb, Ph.D., Jefferson City, has served as the Executive Director of the State Council on Vocational Education and as director, Joint Career Tech Programs, Washington. He has been a member since the council was created in 1985.

Senator Edwin L. Dirck, St. Ann, served as the first chairman of the council from 1985 to 1987. During the summer of 1984, he chaired a Joint Interim Committee on Head Injury which held a series of statewide public hearings. Following the hearings, he introduced and passed the mandatory seat belt law. He also sponsored and passed the legislation establishing and regulating trauma centers and handled the legislation creating the head injury division. He resigned from the Missouri Senate in May 1992, and subsequently from the council.

Judith A. Ferguson, Kimberling City, served as chairman of the Missouri Head Injury Advisory Council from March 1988 through May 1991, when she resigned. She is the founder of the Missouri Head Injury Association and is past vice president of State Association Affairs of the National Head Injury Foundation. She is a family member who has a son who suffered a head injury in 1978.

R. Dale Findlay, Jefferson City, is the director of the Missouri Safety Council and is chairman of the State Injury Control Committee. He has been a member of the council since it was created in 1985.

Robert G. Frank, Ph.D, Columbia, is Associate Professor and Vice Chairman, Department of Physical Medicine and Rehabilitation, School of Medicine, University Hospital and Clinics, University of Missouri. Dr. Frank has served on the council since it was created in 1985.

Don L. Gann, Ed.D., Assistant Commissioner (head) of the Division of Vocational Rehabilitation, Department of Elementary and Secondary Education. He is a member of the National Rehabilitation Association and the Council of State Administrators of Vocational Rehabilitation. He represented the Department of Elementary and Secondary Education on the Joint Interim Committee on Head Injury and has been a council member since it was created.

Charles H. Goforth, Springfield, served as President and Administrator of UpJohn Health Care Ser-

vices serving sixteen counties in Southwest Missouri. He resigned in 1991.

William Hickle, J.D., Rolla, is a partner in the law firm, Carnahan, Carnahan and Hickle. The practice specializes in personal injury litigation, insurance litigation, workers' compensation claims, guardianship and probate, law, and civil trial practice. He was appointed to the council in 1989.

L. Dennis Humphrey, Ed.D., Springfield, is a professor in the Department of Biomedical Sciences, Southwest Missouri State University. He was elected as council Vice-President September 1991. He has been a member since the council was created.

Gerald J. Kampeter, Jefferson City, is the parent of a daughter with a head injury. Before he retired, he worked for the Missouri Highway and Transportation Commission for over 35 years. He has served on the council since it was created in 1985.

Nancy Koenig, Florissant, is the parent of a son who suffered a head injury. She was elected chairman in 1991, and has been a member of the council since 1985. She has served as president of the St. Louis Bi-State Chapter of the Missouri Head Injury Association and as vice president of Operation of the Association. She is also a member of the Productive Living Board for St. Louis County Citizens with Developmental Disabilities.

Jane Y. Kruse, J.D., Jefferson City, previously was the director of the Division of Medical Services and the deputy director, External Operations, Division of Child Support Enforcement, Department of Social Services. She resigned January 1991.

Representative Sheila Lumpe, University City, served as vice chairman of the council from 1988-1991. She served as a member of the Joint Interim Committee on Head Injury during the summer of 1984. During the 1986 legislative session, she sponsored legislation which created the head and spinal cord injury registry and established the Missouri Head Injury Advisory Council. She was replaced in February 1991, by Representative Charles Quincy Troupe.

Representative Carole Roper Park, Sugar Creek, chairs the House Appropriations Committee on Health and Mental Health. She sponsored legislation creating the new head injury division in the Department of Health. She is active in many organizations advocating for persons with developmental disabilities and persons with mental illness. Representative Park was appointed to the council by the Speaker of the House in March 1989.

Charles F. Renn, Jefferson City, served as the Deputy Director, Company Regulations, Department of Insurance, and served on the council until he resigned in 1992.

C. Keith Schafer, Ed.D., Jefferson City, is the director of the Missouri Department of Mental Health. The department operates three service divisions: Division of Alcohol and Drug Abuse, Division of Mental Retardation and Developmental Disabilities, and the Division of Comprehensive Psychiatric Services. Dr. Schafer was appointed to the council in April 1989.

Charles Quincy Troupe, St. Louis, was first elected to the Missouri House of Representatives in 1978. He is chairman of the Appropriations Committee on Social Services and Corrections and a member of Budget Committee.

Nathan B. Walker, Jefferson City, served as the director of the Division of Highway Safety, Department of Public Safety, and as Director of Administration, Office of the Attorney General. He resigned in January 1992.

C. Keith Whittaker, M.D., Kansas City, is a neurosurgeon at St. Luke's Hospital, Kansas City. He is a member of the American Medical Association, Missouri State Medical Society and American College of Surgeons. His term ended May 1991,

Senator Harry Wiggins, Kansas City, served as a member of the Joint Interim Committee on Head injury in 1984. He handled the house bill in the Senate which created the head and spinal cord injury registry. He also sponsored legislation strengthening the DWI law.

Lorna M. Wilson, R.N., C., MSPH, Jefferson City, served as the director of the Division of Local Health and Institutional Services, Department of Health. She was replaced in 1991 by Dr. John Bagby.

About the Staff

Susan L. Vaughn, M.Ed, Jefferson City, is the director of the Missouri Head Injury Advisory Council and has served in that capacity since the council was created. She has over seventeen years of experience in state government and in the field of disabilities. She has previously been employed as a speech therapist at B.W. Sheperd State School for the Severely Handicapped, as a regional coordinator of the Region IX Council on Developmental Disabilities, as staff for the Missouri Planning Council for Developmental Disabilities and as the assistant to the director of the Department of Mental Health. She represented the Department of Mental Health on the Joint Interim Committee on Head Injury in 1984.

Lois M. Lorenz, Jefferson City, is the secretary for the head injury program and has worked for the council since it was created. She has worked in state government of over twelve years having worked for the Department of Mental Health both in the Division of Alcohol and Drug Abuse and for the department director's office. Prior to the department, she worked for the Office of Administration, Division of Personnel.